

Physical Activity and Advanced Cancer: A Grounded Theory Approach

Sonya Stephanie Lowe

Bachelor of Science (First-Class Honours) in Zoology

Master of Science (Thesis) in Oncology

Doctor of Medicine (Honours in Research)

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD programme

August 2017

Faculty of Health and Medicine

Lancaster University

I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

Abstract

Background: Cancer-related fatigue and loss of physical functioning are distressing symptoms which negatively impact the quality of life of people with advanced cancer. Physical activity has been shown to have positive effects on these symptoms in early stage cancer, but previous research has demonstrated an incongruence between people with advanced cancer's expressed interest and actual participation in a physical activity intervention. **Aim:** The aim of this two-phase, cross-sectional study was to gain an in-depth understanding of the experience of activity and quality of life in people with advanced cancer, using a classic grounded theory approach. **Methods:** Phase One involved participants wearing an *activPAL*[™] activity monitor and filling out a daily record sheet for seven days duration; Phase Two involved face-to-face, semi-structured interviews using the daily record sheets and activity monitor outputs as qualitative probes. From an outpatient department of a tertiary cancer centre in Alberta, Canada, theoretical sampling was used to recruit a total of 15 people with advanced cancer and a median survival of 100 days. Data analysis employed classic grounded theory procedures, including core category emergence, constant comparison of indicators to theoretical saturation, and conceptual memoing. **Findings:** *Maintaining responsibility* emerged as the main concern of participants in this study, and *downsizing* to the *critical threshold* of responsibility accounted for how this concern was managed. The grounded theory explains how the *critical threshold* is influenced by conditions unique to people with advanced cancer, and how it is facilitated through activity and other mechanisms. **Conclusion:** Knowledge of this mid-level theory enables researchers and clinicians to understand activity as a mechanism through which the *critical threshold* of responsibility is managed, and to inform future behavioural interventions using a theoretical framework which is aligned with the advanced cancer experience.

Acknowledgements

First and foremost, I would like to extend my greatest appreciation to all the people with advanced cancer, their caregivers and families for the gift of their time and participation.

I would like to acknowledge the Alberta Cancer Foundation Roche Fellowship in Translational Research for funding this research.

Much deserved recognition must be given to Dr. Sarah Brearley and Professor Christine Milligan for their extensive guidance and supervision, and to Dr. Sharon Watanabe and Professor Kerry Courneya for their steadfast encouragement and mentorship.

I am particularly grateful to Dr. Barney Glaser for his constructive feedback and personal instruction which I received at the 2015 Grounded Theory Seminar, and which enriched my methodological development as a researcher.

A special thanks to each and every member of the Department of Symptom Control and Palliative Care, Cross Cancer Institute for their assistance with recruitment. I am especially grateful to Ms. Asifa Mawani for her hands-on assistance during the study.

I am deeply indebted to my parents, Stephen and Theresa Lowe, and my sister Stacey, for their unconditional love and support.

Finally, none of this would be possible without the ceaseless patience and understanding of my husband Dereck, and our sons Noah and Elijah.

Table of Contents

Abstract.....	i
Acknowledgements.....	ii
Chapter 1 – Introduction to the thesis, the significance of advanced cancer, palliative care and quality of life, and the context for the research.....	1
1.1 Introduction	1
1.2 Advanced Cancer and its Impact on Morbidity and Mortality.....	1
1.3 Palliative Care and its Significance in Cancer.....	2
1.4 Quality of Life and its Relevance in Advanced Cancer	3
1.5 Context for the Research	4
1.5.1 Background of the Researcher.....	4
1.5.2 A Change in Research Paradigm	5
1.6 Study Aim and Objectives	6
1.7 Organisation of the Thesis	7
Chapter 2 – Background of cancer-related fatigue, physical functioning and activity as a quality of life intervention in people with advanced cancer	9
2.1 Introduction	9
2.2 Cancer-Related Fatigue, Physical Functioning and Quality of Life.....	9
2.3 Physical Activity in People with Cancer	11
2.4 Physical Activity and Quality of Life in Advanced Cancer	12
2.4.1 Previous Systematic Reviews in Advanced Cancer	13
2.4.2 Previous Studies of the Researcher	13
2.5 Summary	14
Chapter 3 – Philosophical underpinnings, methodological rationale and methods of the study	16
3.1 Introduction	16
3.2 Researcher Reflexivity.....	16
3.3 Qualitative Rationale for the Research	18
3.4 Subtle Realism: The Research Paradigm.....	19
3.5 Classic Grounded Theory: The Research Methodology	20
3.7 Methods.....	23
3.7.1 Study Setting	23
3.7.2 Study Sample	23
3.7.3 Sampling.....	24
3.7.4 Study Recruitment	26

3.7.5 Data Collection.....	26
3.7.6 Data Management	30
3.7.7 Data Analysis and Constant Comparative Technique	30
3.7.8 Study Rigour.....	31
3.7.9 Ethical Considerations.....	32
3.8 Summary	35
Chapter 4: The Process of Conceptual Development using Classic Grounded Theory Method	36
4.1 Introduction	36
4.2 Data: The First Level of Conceptual Perspective Analysis.....	36
4.2.1 Data Familiarisation	36
4.2.2 Data Coding and the Concept-Indicator Model.....	37
4.3 Category: The Second Level of Conceptual Perspective Analysis.....	39
4.3.1 The Core Conceptual Category	39
4.3.2 Constant Comparative Analysis	39
4.4 Memo: The Third Level of Conceptual Perspective Analysis	42
4.5 Summary	46
Chapter 5 - The Emergent Theoretical Framework: The Main Concern and Core Conceptual Category.....	48
5.1 Introduction	48
5.1.1 Study Participant Characteristics	48
5.2 The Main Concern: <i>Maintaining Responsibility</i>	53
5.3 The Core Conceptual Category: <i>Critical Threshold</i>	54
5.3.1 Provision for Self: A Sub-Category of the Critical Threshold	55
5.3.2 Key Relations.....	59
5.3.3 Commitment to Community.....	63
5.4 The Decision-Making Strategy: <i>Downsizing</i>	65
5.5 Summary	67
Chapter 6: The Emergent Theoretical Framework: Benefits, Conditions and Mechanisms....	69
6.1 Introduction	69
6.2 The Benefits of <i>Maintaining Responsibility</i>	69
6.2.1 Purpose	71
6.2.2 Contribution.....	71
6.2.3 Identity.....	71
6.2.4 Accomplishment	72
6.2.5 Locus of Control	72

6.3 The Conditions of <i>Maintaining Responsibility</i>	73
6.3.1 Understanding of Illness	74
6.3.2 Symptom Burden	75
6.3.3 Physical Functioning.....	76
6.3.4 Disease and Symptom Treatment Strategies.....	77
6.3.5 Day-to-Day Fluctuations	77
6.3.6 Acute Stressors	77
6.3.7 Environment Layout.....	78
6.3.8 Person Supports.....	78
6.3.9 Equipment Supports	79
6.4 The Mechanisms of <i>Maintaining Responsibility</i>	79
6.4.1 Delegating	81
6.4.2. Transferring.....	81
6.4.3 Goal Setting.....	82
6.4.4 Day-to-Day Routine.....	83
6.4.5 Path of Least Resistance	83
6.4.6 Pacing	84
6.4.7 Activity	84
6.5 The Dynamic Interplay of the Benefits, Conditions and Mechanisms of <i>Maintaining Responsibility</i>	86
6.7 Summary	86
Chapter 7: A Literature Review of Responsibility in People with Advanced Cancer using a Classic Grounded Theory Approach.....	88
7.1 Introduction	88
7.2 Justification for the Timing and Focus of the Literature Review	88
7.3 Aim of the Literature Review	89
7.4 Review Methods	89
7.4.1 Review Question	89
7.4.2 Review Design	89
7.4.3 Information Sources and Search Strategy	90
7.4.4 Inclusion / Exclusion Criteria.....	92
7.4.5 Identification and Selection of Studies	92
7.4.6 Data Extraction.....	92
7.4.7 Data Analysis and Constant Comparative Technique	93
7.5 Results of the Review.....	93
7.5.1 Overview of Included Studies	93

7.5.2 Findings on the concept of responsibility in people with advanced cancer.....	99
7.6 Discussion.....	103
7.7 Limitations of the Literature Review	108
7.8 Strengths of the Literature Review	108
7.9 Summary	108
Chapter 8: Discussion of activity in people with advanced cancer within the context of <i>Maintaining Responsibility</i> , evaluation of the grounded theory, and reflections on the research process	110
8.1 Introduction	110
8.2 Summary of <i>Maintaining Responsibility</i>	110
8.3 The Experience of Activity in People with Advanced Cancer.....	113
8.3.1 The Meaning of Activity for People with Advanced Cancer	115
8.3.2 The Perceptions of Activity by People with Advanced Cancer	117
8.3.3 Barriers and Facilitators to Activity for People with Advanced Cancer	118
8.4 Evaluating <i>Maintaining Responsibility</i>	121
8.4.1 Fit	121
8.4.2 Work.....	122
8.4.3 Relevance	122
8.4.4 Modifiability.....	123
8.5 Reflections on the Research Process	123
8.6 Summary	124
Chapter 9 – Conclusions to the thesis, contributions to knowledge, implications for research and clinical practice, and evaluation of study limitations and strengths	126
9.1 Introduction	126
9.2 Conclusions of Empirical Findings.....	126
9.3 Contributions to Knowledge and Theory	127
9.4 Implications for Research in Activity and Advanced Cancer.....	128
9.5 Implications for Clinical Practice.....	130
9.6 Study Limitations	131
9.7 Study Strengths.....	132
9.8 Final Conclusion	133
References	135
Appendix A: Ethical Approval.....	143
Appendix B: Physician Request Letter	147
Appendix C: Consent Form	148
Appendix D: Daily Symptom Record Sheet.....	156

Appendix E: Sample Activity Monitor Output.....	157
Appendix F: Semi-structured Interview Guide.....	159
Appendix G: Sample of Open Coding.....	160
Appendix H: List of Codes	162
Appendix I: List of Code Families	172
Appendix J: List of Memos	174
Appendix K: Sample Search Strategies for Web of Science, PsycINFO, Academic Search Complete, and CINAHL.....	187
Appendix L: Data Extraction Form	191

Tables

Table 1: Participant Characteristics from Initial Cycle of Open Sampling.....	50
Table 2: Participant Characteristics from Subsequent Cycle of Theoretical Sampling.....	52
Table 3: Key Terms for the Literature Review.....	90
Table 4: Sample Search Strategy for MEDLINE (PubMed).....	91
Table 5: Data Extraction from Included Studies.....	95

Figures

Figure 1: Historical Evolution of Grounded Theory Method.....	21
Figure 2: Flow Chart of Sampling for Study.....	25
Figure 3: Flow Chart of Data Collection for Study.....	27
Figure 4: The Sub-Categories of the <i>Critical Threshold: Provision for Self, Key Relations and Commitment to Community</i>	55
Figure 5: The Dimensions of <i>Provision for Self: Self-Care, Self-Management of Health and Self-Sufficiency</i>	56
Figure 6: The Properties of <i>Self-Care: Symptom Control and Respect for Limitations</i>	58
Figure 7: The Dimensions of <i>Key Relations: Role of Caregiver, Role of Spouse, Role of Adult Child, Role of Parent, and Role of Grandparent</i>	60
Figure 8: The Dimensions of <i>Commitment to Community: Vocation and Society</i>	64
Figure 9: <i>Downsizing to the Critical Threshold: A State of Flux</i>	67
Figure 10: The Benefits of <i>Maintaining Responsibility</i>	70
Figure 11: The Conditions of <i>Maintaining Responsibility</i>	74
Figure 12: The Mechanisms of <i>Maintaining Responsibility</i>	81
Figure 13: The Dynamic Interplay of Benefits, Conditions and Mechanisms.....	86
Figure 14: PRISMA flow diagram for study selection.....	94
Figure 15: Everyday Matters: A Property of Day-to-Day Routine.....	105
Figure 16: Uncertainty and Disequilibrium: A Property of Day-to-Day Fluctuations and Acute Stressors.....	106
Figure 17: Autonomy: A Property of <i>Self-Sufficiency</i>	107
Figure 18: Staying Connected and Feeling Supported: Benefits of <i>Maintaining Responsibility</i>	107
Figure 19: The Grounded Theory of <i>Maintaining Responsibility</i>	112

Images

Image 1: The <i>activPAL</i> [™] activity monitor placement on the researcher's leg.....	27
---	----

Chapter 1 – Introduction to the thesis, the significance of advanced cancer, palliative care and quality of life, and the context for the research

1.1 Introduction

This chapter introduces this study of activity in people with advanced cancer using a classic grounded theory approach. In the first section, a brief description of the importance of advanced cancer, palliative care and quality of life is provided. In the second section, the context for the research, including the researcher's background and the research paradigm, is highlighted. The study aims and objectives are presented. Lastly, a chapter-by-chapter outline of the thesis structure is provided.

1.2 Advanced Cancer and its Impact on Morbidity and Mortality

Cancer is amongst the foremost causes of morbidity and mortality worldwide (Fidler, Bray, & Soerjomataram, 2017). Globally, cancer is the second leading cause of death, with an estimated 14.1 million new cancer cases and 8.2 million cancer deaths in 2012 (Torre et al., 2015). In Canada, cancer is the leading cause of death, with an estimated 206,200 new cases of cancer and 80,800 deaths from cancer in 2017 (CCS, 2017). Nearly one out of every six people worldwide (WHO, 2017), and one out of every four people in Canada (CCS, 2017), are expected to die from cancer. Due to the rapid growth and aging of populations (WHO, 2002), the global burden of cancer is projected to rise. Cancer thus impacts the well-being and lives of more people than ever before.

The morbidity and mortality from cancer increases as people progress along the disease trajectory (Allemani et al., 2015). Although varying definitions have been employed (Hui et al., 2016), advanced cancer refers to disease that has spread from the primary site to other areas of the body, and which cannot be cured or controlled by treatment. Despite advances

in early identification and treatment, mortality for advanced cancer, particularly of the lung, pancreas and biliary tract, remains very high (Haun et al., 2017). Along with the rising global incidence of cancer, the number of people with advanced cancer continues to grow. The morbidity and mortality from advanced cancer thus impacts the suffering and premature death of ever greater numbers of people worldwide.

1.3 Palliative Care and its Significance in Cancer

Palliative care is the interdisciplinary and holistic approach to the identification, assessment and management of physical, psychosocial and spiritual problems associated with life-threatening illness (WHO, 2015). Palliative care aims to alleviate suffering, and to assist people in living according to their specific needs and preferences as much as possible until death. In 2011, approximately 20.4 million people around the world were in need of palliative care at the end of life (WHO, 2014). Non-communicable illnesses, including cancer, cardiovascular disease, and chronic obstructive pulmonary disease, account for an estimated 90% of the global burden of palliative care at the end of life (WHO, 2014). Given the increase in ageing populations and non-communicable disease burden (UN, 2015), palliative care is becoming all the more relevant.

Palliative care is increasingly viewed as being fundamental to comprehensive cancer care (Glare, 2013). Worldwide, 34% of adults in need of palliative care died from cancer (WHO, 2014). In Canada, approximately 45% of people with cancer die in acute care settings, despite a majority preference to die at home (CCS, 2016). The increased need for palliative care has resulted in its endorsement as a national priority by the House of Parliament (Canada, 2014), and by over thirty national organizations in the Quality End-of-Life Care Coalition of Canada (QELCCC, 2010). The rise in cancer incidence and subsequent deaths from cancer speaks to the growing importance of palliative care in addressing the physical, psychosocial and spiritual issues faced by people with cancer.

1.4 Quality of Life and its Relevance in Advanced Cancer

The primary goal of palliative care is to optimise quality of life, which is a subjective, multidimensional construct encompassing several aspects of physical and psychosocial well-being (Cella, 1994). Quality of life accounts for how individuals perceive their lives to be, taking everything into consideration (Kaasa & Loge, 2003), and also encompasses a wide range of indicators, including symptom control, existential and spiritual concerns, and family coping and support (Conrad et al., 2017). Although it has been shown to improve quality of life at earlier stages in the cancer trajectory (Hui & Bruera, 2016), palliative care plays a principal role in the last months of life wherein disease progression is accompanied by a decline in overall quality of life (Giesinger et al., 2011; Seow et al., 2011). Given the high mortality and significant morbidity of advanced cancer, the need to maximise quality of life is particularly imperative.

In advanced cancer, increasing symptom burden and intensity leads to deterioration in quality of life (Gilbertson-White, Aouizerat, Jahan, & Miaskowski, 2011). In a systematic review of 44 studies examining symptom prevalence in people with incurable cancer, greater than 50% experienced fatigue, loss of energy, pain, appetite loss and weakness (Teunissen et al., 2007). Cancer-related fatigue and loss of physical functioning are amongst the most distressing symptoms experienced by people with cancer, with detrimental impact on their quality of life (Jordhoy et al., 2007; NCCN, 2016). The European Association of Palliative Care's working definition of fatigue is "a subjective feeling of tiredness, weakness or lack of energy" (Radbruch et al., 2008, p. 15); physical functioning is an individual's perception of ability to carry out these activities (Jordhoy et al., 2007). The impact of cancer-related fatigue and loss of physical functioning on the quality of life of people with advanced cancer will be further explored in Chapter 2 of this thesis.

1.5 Context for the Research

1.5.1 Background of the Researcher

Professionally, I have been a palliative care physician consultant for 10 years, working as a member of a multidisciplinary team providing palliative care in a variety of health care settings in Edmonton, Canada. In my clinical role, I see how prevalent cancer-related fatigue and loss of physical functioning are, and how much these symptoms contribute to poor quality of life in people with advanced cancer. In order to provide better clinical care, I am seeking different interventions, both pharmacological and non-pharmacological, that could ameliorate these symptoms and improve the quality of life of people with advanced cancer. Personally, I am physically active, and received training in group fitness instruction. I have witnessed how physical activity improves quality of life for me and for other people. Both my professional background and personal experience sparked my interest in physical activity as a potential intervention to improve quality of life for people with advanced cancer.

Prior to my PhD studies, I conducted a systematic review that showed that there was insufficient evidence to evaluate the efficacy of physical activity interventions in people with advanced cancer (Lowe, Watanabe, & Courneya, 2009). I subsequently administered a pilot survey to 50 advanced cancer participants (Lowe, Watanabe, Baracos, & Courneya, 2009), the majority of whom indicated that they would be interested in and felt able to participate in a physical activity intervention (Lowe, Watanabe, Baracos, & Courneya, 2010). Informed by the participants' interests and preferences (Lowe et al., 2010), I developed a home-based functional walking programme for a feasibility trial. However, there was low recruitment and high attrition, with only three of the nine recruited participants completing the intervention (Lowe, Watanabe, Baracos, & Courneya, 2013). Overall, there was an incongruence between the high level of interest in physical activity expressed by people with advanced cancer

(Lowe, Watanabe, Baracos, et al., 2009; Lowe et al., 2010), and their low level of actual participation in a physical activity intervention (Lowe et al., 2013).

As the researcher, I began with a set of assumptions informed by my professional background and personal experience. As a palliative care physician, my training and practice are situated within the positivist-empiricist paradigm of evidence-based medicine (Sackett et al., 1996). Positivism-empiricism is adopted by a growing body of physical activity research (Ferreira et al., 2012; Reiner, Niermann, Jekauc, & Woll, 2013; Warburton et al., 2010), including my previous quantitative studies (Lowe, Watanabe, Baracos, et al., 2009; Lowe et al., 2010, 2013). Through being and teaching others to be physically active, my underlying assumption was that physical activity is fundamentally good, and that what is beneficial for healthy adults should be beneficial for the quality of life of all people. This study, however, arose from reflexive awareness that these assumptions may themselves be the barriers which prevented me from explaining the disparity between expressed interest and actual participation in physical activity in people with advanced cancer.

1.5.2 A Change in Research Paradigm

I approached this study through the post-positivist lens of subtle realism, which endorses activity as an independent and tangible entity, but which can only be accessed indirectly through understanding others' perspectives of that reality (Madill, 2008; Maxwell, 2012). For this study, I adopted classic grounded theory methodology, whose aim is to generate theory that emerges from social behaviour, without any preconceived theory that predetermines what concepts or hypotheses might be relevant (Glaser, 1978, 1992; Glaser & Strauss, 1967). Rather than applying extant theory about physical activity and cancer, I challenged my previous positivist-empiricist beliefs and developed a new theoretical framework which is grounded in and applicable to the advanced cancer experience.

True to classic grounded theory method, a literature review was not conducted *a priori* so as not to impose preconceived ideas or assumptions on the emergent theoretical framework (Glaser, 1998). Because of my previous systematic review in physical activity and advanced cancer (Lowe, Watanabe, & Courneya, 2009), I could not attain a true *tabula rasa* perspective, nor do Glaser and Strauss (1967) endorse this. The findings from my previous studies, however, demonstrated an incongruence between people with advanced cancer's expressed interest and actual participation in physical activity, and provided the context from which the impetus for this study originated (Lowe, Watanabe, Baracos, et al., 2009; Lowe et al., 2010, 2013). As such, the literature review for this study was conducted subsequent to the emergent theoretical framework, and could not have been anticipated beforehand because it was based upon the core conceptual category that was empirically grounded in the study data.

1.6 Study Aim and Objectives

The research problem is to explain the disparity between expressed interest and actual participation in physical activity in people with advanced cancer. The aim of this study is to gain an in-depth understanding of the experience of activity and quality of life in people with advanced cancer. The objectives of this study are:

- 1) To explore the meaning of activity for people with advanced cancer in the context of their day-to-day life
- 2) To elicit people with advanced cancer's perceptions of activity with respect to their quality of life
- 3) To elicit people with advanced cancer's views of barriers and facilitators to activity in the context of their day-to-day life.

1.7 Organisation of the Thesis

The organisation of this thesis reflects my methodological journey and adherence to a classic grounded theory approach throughout the process of this study. The structure of the thesis is as follows:

In Chapter 2, a contextual overview of cancer-related fatigue, physical functioning, and the role of activity as a quality of life intervention in people with cancer is presented. The course of my previous studies is traced, leading up to the identification of the research problem.

In Chapter 3, reflexivity is examined through the positivist-empiricist assumptions and epistemic-ontological underpinnings of the research. A justification of the study methodology, including the choice of subtle realism and classic grounded theory, is provided. The study methods, including data collection and analysis procedures, are presented.

In Chapter 4, the process of conceptual development is illustrated step-by-step using specific examples of concepts as they emerged through the study, in keeping with a classic grounded theory approach. The use of core conceptual emergence is traced, from empirical data to open coding for indicators of concepts, which were then constantly compared through interchangeability of indicators to reach theoretical saturation. The concurrent progression from open to selective coding, from conceptual to theoretical memoing, is highlighted.

In Chapters 5 and 6, the emergent theoretical framework from this study of activity in people with advanced cancer is presented. In Chapter 5, the participant characteristics are described in the first section. The participants' main concern and the core categorical variable are identified; the strategy by which participants manage their main concern, is explained. In Chapter 6, the typology of benefits, conditions and mechanisms which enable participants to manage their main concern, is detailed. All study participants are represented in Chapters 5 and 6, and concepts are illustrated through the use of participant quotations.

In Chapter 7, a literature review of the core conceptual category in people with advanced cancer using a classic grounded theory approach, is presented. By interrogating included studies as primary data for constant comparative analysis, related concepts were identified. Implications of the literature review findings for the emergent theoretical framework are discussed.

In Chapter 8, the grounded theory from this study of activity in people with advanced cancer is summarized. The implications of this grounded theory on the thesis aim and objectives, and in the context of the extant literature, are discussed. Evaluation of the grounded theory, and researcher reflexivity, are briefly commented upon.

In Chapter 9, conclusions to the empirical findings are highlighted. This thesis' contributions to knowledge and methodology, evaluation of study strengths and limitations, and recommendations for practice and future research, are presented.

Chapter 2 – Background of cancer-related fatigue, physical functioning and activity as a quality of life intervention in people with advanced cancer

2.1 Introduction

This chapter situates the research within a contextual background of cancer-related fatigue, physical functioning and quality of life in people with advanced cancer, and introduces activity as a behavioural intervention to address these outcomes. This overview is purposefully broad in scope, as I suspended engagement with extant literature so as to minimize the risk of preconceiving the grounded theory (Holton & Walsh, 2017). In the first section, cancer-related fatigue and loss of physical functioning as it pertains to quality of life of people with advanced cancer, is discussed. In the second section, physical activity as a potential intervention to improve quality of life in people with advanced cancer is considered. Lastly, an overview of the researcher's previous studies is provided, which leads to the identification of the research problem.

2.2 Cancer-Related Fatigue, Physical Functioning and Quality of Life

Quality of life is negatively impacted by cancer-related fatigue, which is reported as the most common and distressing symptom experienced by people with cancer (NCCN, 2016). Not only is it persistent, but cancer-related fatigue is disproportionate to the individual's level of exertion and is not alleviated by sleep or rest. In a systematic review and meta-analysis of older people with cancer receiving palliative care, fatigue was the most prevalent symptom with a pooled prevalence of 77.8% (Van Lancker et al., 2014). In a cross-sectional survey of 3,030 people with cancer from European palliative care centres, the two most prevalent symptoms were generalized weakness (50%) and fatigue (48%) (Laugsand et al., 2009). Similarly, in a multivariate analysis of 1,000 people with cancer referred to an American palliative care programme, fatigue and weakness were present in 69% and 66%, respectively

(Walsh, Donnelly, & Rybicki, 2000). In addition to its high prevalence, severe fatigue is significantly associated with poor quality of life in people with terminal cancer, even in the absence of chemotherapy, hormone therapy or immunotherapy (Rodrigues et al., 2016).

Cancer-related fatigue is a subjective, multidimensional symptom that is postulated to involve concomitant dysregulation of physiological, biochemical and psychological processes (Ryan et al., 2007). Peripheral fatigue, which is perceived by the person with cancer as weakness or lack of energy, may be related to alterations of adenosine triphosphate metabolism in the skeletal muscle (Agteresch et al., 2000). An increase in serotonin levels, or upregulation/hypersensitivity of serotonin receptors, may decrease somatomotor drive, and lead to the individual's perception of reduced capacity to perform physical tasks (Andrews, Morrow, Hickok, & al., 2004). Disturbances of the hypothalamic-pituitary-adrenal axis (HPA) are also hypothesized to play a role in cancer-related fatigue: higher levels of pro-inflammatory cytokines, such as tumour necrosis factor- α and interleukin-1, stimulate the HPA (Bower, Ganz, Aziz, & Fahey, 2002), whereas cancer treatment, such as radiotherapy, glucocorticoids and select chemotherapy, can directly suppress the HPA (Schmiegelow et al., 2003). Cancer-related fatigue may also be modulated by circadian rhythm disruption due to changes in temperature, levels of endocrine factors (i.e. cortisol, melatonin and prolactin), levels of immune factors (i.e. leukocytes and neutrophils) and changes in rest-activity patterns which have been linked to cancer progression (Eismann, Lush, & Sephton, 2010). Comorbid conditions such as anaemia, anorexia-cachexia, depression and sleep disturbances may also exacerbate cancer-related fatigue and contribute to poor quality of life (Ryan et al., 2007). Its multidimensional pathogenesis is manifest in the diverse ways in which cancer-related fatigue impacts quality of life in people with advanced cancer.

A characteristic of cancer-related fatigue is its interference with usual functioning (Watson & Mock, 2004). In a population-based survey of 374 people with cancer and a prior history of

chemotherapy, 91% reported that fatigue “prevented them from leading a ‘normal’ life” (Curt et al., 2000, p. 356). Cancer-related fatigue can impair an individual’s ability to perform basic activities of daily living (BADLs), such as bathing and transferring positions, and instrumental activities of daily living (IADLs), such as housework and preparing meals (Struck & Ross, 2006). Loss of the ability to do what one wants has been identified as one of the highest-rated end-of-life concerns from the perspective of both individuals and caregivers (Axelsson & Sjoden, 1998). In conjunction with anorexia-cachexia, weight loss, and deconditioning (Jordhoy et al., 2007), cancer-related fatigue contributes to loss of physical functioning, physical decline and progressive debility to the detriment of the individual’s quality of life.

2.3 Physical Activity in People with Cancer

Given the negative impact of cancer-related fatigue and loss of physical functioning on quality of life in people with cancer, recent attention has been given to behavioural interventions to try to improve these outcomes (McMillan & Newhouse, 2011). Physical activity is one type of behavioural intervention which has been found to improve fatigue and physical functioning outcomes in healthy adult populations (Ferreira et al., 2012; Reiner et al., 2013; Warburton et al., 2010). Physical activity is defined as any bodily movement produced by the skeletal muscles that results in a substantial increase in energy expenditure over resting levels; in contrast, exercise is any form of physical activity undertaken by an individual during leisure time and performed repeatedly over an extended period with the goal of improving fitness or health (Bouchard & Shephard, 1994). Within the cancer trajectory, interest in behavioural interventions as a means to improve quality of life has predominantly focused on people with early stage cancer and moderate-to-vigorous intensity exercise interventions (Courneya & Friedenreich, 2007).

Multiple systematic reviews highlight a growing consensus that moderate- to vigorous-intensity physical activity can improve several aspects of physical and psychological wellbeing that contribute to quality of life in people with early stage cancer (Fong et al., 2012; Mishra, Scherer, Snyder, et al., 2012; Speck et al., 2010). In a recent meta-analysis of 113 randomised trials, exercise was shown to significantly decrease the severity of cancer-related fatigue, with interventions being most effective in early stage, non-metastatic cancers (Mustian et al., 2017). The subsequent clinical recommendation is that exercise and psychological interventions should be given as first-line treatment for cancer-related fatigue (Mayor, 2017). The American Cancer Society's most recent guidelines recommend regular exercise to people with cancer both during and after treatment, for improved quality of life (Rock et al., 2012). These conclusions, however, are drawn from an evidence base that is largely restricted to people with early stage cancer who are able to participate in moderate- to vigorous-intensity exercise interventions.

2.4 Physical Activity and Quality of Life in Advanced Cancer

Although there are numerous interdisciplinary guidelines advocating the use of physical activity interventions to improve quality of life in people with early stage cancer (Segal et al., 2017), there are no specific guidelines regarding physical activity for people with advanced cancer. The 2010 American College of Sports Medicine Roundtable on Exercise Guidelines for Cancer Survivors recommends that "the advice to 'avoid inactivity', even in cancer patients with existing disease or undergoing difficult treatments, is likely helpful" (Schmitz et al., 2010, p. 1415). Given that disease progression is associated with worsened fatigue, loss of physical functioning and decline in overall quality of life (Giesinger et al., 2011), there is a lack of clarity about whether physical activity can positively impact these outcomes in people with advanced cancer.

2.4.1 Previous Systematic Reviews in Advanced Cancer

I conducted a systematic review that showed preliminary evidence that at least some people with advanced cancer were able to tolerate physical activity interventions, with some demonstrating improvement in quality of life outcomes post-intervention (Lowe, Watanabe, & Courneya, 2009). A subsequent review concluded that there was insufficient evidence to support the efficacy of exercise as an intervention in people with metastatic cancer (Beaton et al., 2009). Another review identified preliminary studies supporting the feasibility of physical activity interventions in people with advanced cancer (Albrecht & Taylor, 2012). Across the reviewed studies, there was heterogeneity in the definition of the advanced cancer, the types of administered interventions and the quality of life outcomes measured. Although some preliminary studies demonstrated feasibility of some physical activity interventions in select participants, it is not clear which person with advanced cancer would be optimal for what type of intervention. Overall, these systematic reviews reveal uncertainty regarding the role of physical activity interventions in people with advanced cancer (Albrecht & Taylor, 2012; Beaton et al., 2009; Lowe, Watanabe, & Courneya, 2009). All three systematic reviews concur that further piloting and early phase development studies are needed in this population.

2.4.2 Previous Studies of the Researcher

I conducted a pilot survey which aimed to examine the association between physical activity and quality of life in people with advanced cancer receiving palliative care (Lowe, Watanabe, Baracos, et al., 2009). Fifty participants, with a median survival of 104 days from time of survey to time of death, were recruited from an outpatient palliative care clinic and palliative home care in Edmonton, Canada. Walking was the most common reported physical activity, and there was a positive association between participants who reported walking 30 min or more per day and higher existential, support and total quality of life scores on the McGill Quality of Life Questionnaire. The majority of participants indicated that they would

be interested in and felt able to participate in a physical activity programme, with a majority preference for walking and home-based programmes (Lowe et al., 2010).

I then conducted a pilot study whose aim was to examine the initial development and feasibility of a home-based functional walking programme in people with advanced cancer receiving palliative care (Lowe et al., 2013). Taking the participants' interests and preferences into account (Lowe et al., 2010), a six-week, home-based intervention was developed, and which involved a daily walking programme with a supervised strength training component 3 times per week. Using the same recruitment strategy as the survey (Lowe, Watanabe, Baracos, et al., 2009), I conducted a pilot uncontrolled pre- to post-intervention trial in a sample of advanced cancer participants with a median survival of 92 days (Lowe et al., 2013). There was, however, low recruitment and high attrition, with only three of the nine recruited participants completing the intervention (Lowe et al., 2013).

Despite a positive association between participant-reported physical activity and quality of life (Lowe, Watanabe, Baracos, et al., 2009), and declared interest to participate in a physical activity programme (Lowe et al., 2010), these findings did not translate into the feasibility of a physical activity intervention in people with advanced cancer (Lowe et al., 2013). My use of extant theory, within a positivist-empiricist paradigm, did not enable me to explain this disparity between expressed interest and actual participation in physical activity by people with advanced cancer (Lowe, Watanabe, Baracos, & Courneya, 2012).

2.5 Summary

Chapter 2 described the negative impact of cancer-related fatigue and loss of physical functioning on the quality of life of people with advanced cancer. Physical activity is one type of behavioural intervention that has demonstrated positive effects on cancer-related fatigue and physical functioning outcomes in people with early stage cancer, however there is uncertainty as to the role of physical activity interventions in people with advanced cancer.

My previous studies identified an incongruence between expressed interest and actual participation in physical activity by people with advanced cancer. This led to me re-evaluating my epistemic-ontological approach to the research, which will be explored in Chapter 3, along with the philosophical underpinnings and methodological rationale for this study.

Chapter 3 – Philosophical underpinnings, methodological rationale and methods of the study

3.1 Introduction

This chapter will justify the epistemic-ontological and methodological approach for this study of activity in people with advanced cancer. In the first section, researcher reflexivity and the qualitative rationale for this study are discussed. In the second section, a justification for the selection of subtle realism and classic grounded theory is provided. Lastly, the study methods are detailed, including design, sampling and data collection procedures, using a classic grounded theory approach. Content drawn from this chapter was published as a methodological paper in *International Journal of Qualitative Methods* (Lowe, Milligan, Watanabe, & Brearley, 2015).

3.2 Researcher Reflexivity

Research is an interactive endeavour shaped by the researcher's personal history and characteristics including gender, social class, race and ethnicity (Denzin & Lincoln, 2011). My clinical training and practice has been conducted within the paradigm of evidence-based medicine (EBM), which is defined as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett et al., 1996, p. 71). Goldenberg (2006) argues that EBM is fundamentally positivist in its "elimination of culture, contexts and the subjects of knowledge production from consideration" (p.2622). In keeping with the positivist-empiricist paradigm, EBM assumes that any claim must stand or fall in light of objective and value-free facts about the world. My clinical education and training prioritized quantitative methodology, with randomized controlled trials being considered the gold standard in the hierarchy of evidence (Kaptchuk, 2001).

By being epistemologically reflexive, I reflected upon the assumptions about the nature of the world and the nature of knowledge, and the implications of these assumptions for the

research and its results (Willig, 2008a). The predominant paradigm in physical activity research is positivism-empiricism (Wheeler, 1998). The assumption that physical activity is a positive intervention for healthy adults (Ferreira et al., 2012; Reiner et al., 2013; Warburton et al., 2010), and for people with cancer and undergoing active treatment (Mishra, Scherer, Geigle, et al., 2012; Mishra, Scherer, Snyder, et al., 2012) is substantiated by a large body of quantitative, rational-empirical evidence. This quantitative focus, and the positivist-empiricist assumptions underlying physical activity research, would suggest that what is beneficial for healthy adults and people with early stage cancer, should also be good for people with advanced cancer.

By being personally reflexive, I reflected upon the ways in which my own experiences, values, beliefs, interests and social identities have influenced my research (Willig, 2008b). In conjunction with my professional background, my personal experiences have likewise influenced my research interests. I have both seen and experienced the positive effects of physical activity on quality of life through teaching adults to be more physically active, and being physically active myself. Each of these anecdotal experiences has informed my previous assumption that physical activity is good for people.

My positivist-empiricist approach and my assumption of the inherently positive nature of physical activity became the perceptual lenses through which I addressed research in the past. The quantitative methodology which I previously used may itself have been the barrier which prevented me from understanding the disparity between expressed interest and actual participation in physical activity by people with advanced cancer. Had I continued to follow my previous positivist assumptions then the resulting research would be “merely the production of bricks rather than a systematic approach to building knowledge based on sound theoretical modelling” (Wheeler, 1998, p. 243).

Rather than borrowing extant concepts and replicating studies within the positivist paradigm, I accepted the fallibility of my previous assumptions: physical activity may not be fundamentally good for all people, and what is beneficial for healthy people and people with early stage cancer, may not be for those people with advanced cancer. My previous research demonstrated that extant theoretical frameworks about physical activity in cancer cannot be applied as if “one size fits all”; indeed, as these were not developed from research in the advanced cancer population, they may not be applicable. I recognized the need to develop an approach to inquiry that is grounded in the participant’s experience, in order to generate theoretical frameworks that are relevant and have utility for people with advanced cancer.

3.3 Qualitative Rationale for the Research

According to the updated UK Medical Research Council guidance, the failure of the implementation of a complex intervention necessitates thorough evaluation of the processes and underlying assumptions which were made during the development stage (Craig et al., 2008). The findings from my previous research highlighted a tension between the *etic* (outsider) perspective regarding the “predominantly positive face” of physical activity (Wheeler, 1998, p. 242), and the *emic* (insider) perspective of people with advanced cancer on participation in physical activity. There is a marked contrast between the *etic* belief that physical activity is inherently positive, and the *emic* experience of the person with advanced cancer who is faced with a physical activity programme.

As introduced in section 1.6 of Chapter 1, the aim of this study is to explore the experience of activity and quality of life in people with advanced cancer. The objectives of this study are to elicit the meaning, perceptions, barriers and facilitators of activity for people with advanced cancer in the context of their day-to-day life. A qualitative methodology, therefore, is most appropriate to gain an in-depth understanding of the *emic* experience of activity and quality of life in people with advanced cancer.

3.4 Subtle Realism: The Research Paradigm

The selection of a research paradigm encompasses the nature of reality (ontology), and how reality can be apprehended (epistemology) (Allsopp, 2013). Historically, the advent of the mid-20th century heralded a reflexive shift in the form of post-positivism (A. B. Ryan, 2006). This allowed for subjective interpretations of what was acceptable as truth, and argued for plausibility by searching for evidence to establish credibility of claims (Madill, 2008). Realism is the post-positivist philosophy, which unites ontological realism with epistemological relativism. Realists assert that : 1) there is more than one way to understand reality, 2) all understanding is relative to a particular perspective or world view, and 3) all knowledge is fallible and can only be partially apprehended (Maxwell & Mittapalli, 2007).

Although distinctions between middle-ground realist positions exist, Seale (1999) contends that “subtle realism provides a pragmatic philosophical rationale for researchers locating their practice within a constructively self-critical research community” (Seale, 1999, p. 30). Subtle realism endorses a naïve realist ontology in that an independent reality is seen to exist, but asserts that this reality can only be accessed indirectly. Subtle realism endorses naïve realist epistemology in that reality is knowable, but contends that this knowledge is merely one representation of possible valid accounts (Madill, 2008). Given that direct apprehension of reality is not possible in subtle realism, knowledge of reality can never be absolutely certain. The criteria adopted by subtle realists include: 1) plausibility with respect to extant knowledge, 2) credibility given what would be reasonably expected under the conditions, and 3) relevance to issues of concern (Madill, 2008).

Subtle realism fits with my belief that activity is a tangible entity that exists independently of my view or others’ views of it, although it may not be possible to directly access that reality. Subtle realists view causality as inherently local, and thus seek to understand site-specific causal explanations rather than generate universal laws. Situational contingencies are

specific local factors associated with the entity under study; subtle realism fits with my belief that examining these situational contingencies may further illuminate the disparity between expressed interest and actual participation in activity by people with advanced cancer.

3.5 Classic Grounded Theory: The Research Methodology

In keeping with my subtle realist stance, I looked towards grounded theory as the research methodology that would enable me to develop a new theoretical framework that is aligned with the advanced cancer experience. Glaser and Strauss (1967) originated grounded theory methodology in response to the positivist paradigm and quantitative methodologies that prioritised verification of theory in the mid-1960s. *The Discovery of Grounded Theory* (1967) described the systematic, concurrent collection, coding and analysis of social research data for the primary purpose of generating new theory (Willig, 2008b). I chose grounded theory as the methodology that would permit me to discover the reason underlying the incongruence between expressed interest and actual behaviour of people with advanced cancer, by remaining open to the emergence of concepts from the data (Glaser & Strauss, 1967).

The aim of classic grounded theory is to ensure that the generated theory will closely correspond to the real world (Glaser & Strauss, 1967), reflecting an objectivist stance (Engward, 2013). Whilst not endorsing a *tabula rasa* perspective, Glaser and Strauss (1967) advocate that the researcher should approach data without any preconceived theory that predetermines what concepts or hypotheses might be relevant. I believe this is particularly salient for my study given my previous research in physical activity and advanced cancer. As such, my stance aligns with the classic view that comparisons with extant literature and theory should be conducted after the core conceptual categories have emerged, in order to facilitate integration (Walls, Parahoo, & Fleming, 2010).

Grounded theory methodology requires: 1) constant comparative analysis wherein similarities and differences are compared between any groups that indicate the same conceptual categories and properties, and across multiple theoretically-sampled cases, 2) theoretical sampling wherein the emerging theoretical framework determines where and what data to collect next, and 3) theoretical saturation wherein recurrence of similar instances with no other additional data contributing to the properties of the core conceptual category (Holton & Walsh, 2017). To be truly grounded, theory must both *fit* and *work*: *fit* refers to being indicated by or applicable to the data, whereas the *work* refers to being able to explain or be relevant to the data (Glaser & Strauss, 1967). *Fitness* and *workability* can never be forced, but are properties that emerge from the data under study. Because extant theory did not enable me to bridge the knowledge gap identified by my previous research, the *fitness* and *workability* of grounded theory can generate a theoretical framework that is relevant to and useful for people with advanced cancer.

Although the key elements of constant comparative analysis, theoretical sampling and theoretical saturation have remained consistent with grounded theory, two further iterations of grounded theory methods have evolved (see Figure 1):

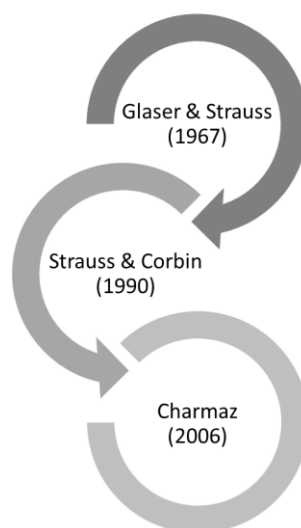


Figure 1. Historical Evolution of Grounded Theory Method

Following a period of renewed interest in interactionism and the role of the researcher as an active participant in the research process (Willig, 2008b), Strauss and Corbin (1990) diverged from classic grounded theory by emphasizing the processual and purposeful nature of action/interaction being present in all phenomena. This predicated their use of axial coding procedures as the means by which data are fragmented, conceptualized, and re-assembled in new ways (Strauss & Corbin, 1990). Although Strauss and Corbin's (1990) emphasis on conditions may share similarities to a subtle realist perspective on situational contingencies, Glaser (1992) argues that the use of axial coding and conditional matrix may force data to conform to preconceived categories. In view of challenging my previous assumptions regarding physical activity in people with advanced cancer, my stance therefore aligns with the classic grounded theory approach, which is less prescriptive and more open to what emerges from the data (Glaser & Strauss, 1967).

Propelled by renewed interest in social constructionism and symbolic interactionism that characterised the beginning of the 21st century (Willig, 2008c), Charmaz (2006) diverged from Strauss and Corbin's (1990) model by rejecting the notion of theoretical emergence or discovery, and emphasized that "we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices" (Charmaz, 2006, p. 10). The focus of Charmazian grounded theory, therefore, is uncovering participants' taken-for-granted or hidden assumptions, meanings, language and rules. Although I concur that reflexivity is critical during the research process, my subtle realist stance conflicts with Charmaz's (2006) belief that the empirical world does not exist independently of human experience. Unlike Charmaz (2006), I do not believe that participants' views and researcher's theoretical renderings are multiple and equally valid constructions of reality. Instead, a classic grounded theory approach is most congruent with my subtle realist stance, and

would enable me to discover those concepts which contribute to the disparity between expressed interest and actual participation in activity by people with advanced cancer.

3.7 Methods

3.7.1 Study Setting

This study was carried out at the Department of Symptom Control and Palliative Care, Cross Cancer Institute in Edmonton, Canada. The Cross Cancer Institute serves a catchment area of nearly 1.5 million people, and is one of two tertiary cancer centres in the province of Alberta (Fairchild et al., 2009). The Department of Symptom Control and Palliative Care offers both inpatient and outpatient consultation services at the Cross Cancer Institute, and provided a total of 828 consults in 2015-2016 (EZPCP, 2016). Although I previously worked in this location, I did not have a clinical role in the Department for the duration of this study.

This location was selected because I have knowledge of and previous experience in local recruitment, including participant-related and gatekeeping issues which are challenging in palliative care trials (LeBlanc, Lodato, Currow, & Abernethy, 2013). Conducting this study locally enabled me easier access to participants. By choosing the same setting as my previous studies (Lowe, Watanabe, Baracos, et al., 2009; Lowe et al., 2013), I was able to explore the disparity between expressed interest and actual participation in physical activity by people with advanced cancer, in a similar context wherein the incongruence was initially discovered.

3.7.2 Study Sample

People with advanced cancer were recruited through an outpatient palliative care department at a tertiary cancer centre in Edmonton, Canada. Participant characteristics are reported in detail as part of the study findings in Chapter Five.

3.7.2.1 Inclusion Criteria

- 18 years of age or older,
- Ability to understand, provide written informed consent in, and speak English,
- Diagnosis of advanced cancer, which is defined as progressive, incurable, and locally recurrent or metastatic disease,
- Clinician-estimated life expectancy of less than 12 months,
- Cognitively intact, which is defined as a Mini-Mental State examination score at or above the level expected for person's age and education level (Crum, Anthony, Bassett, & Folstein, 1993),
- Approval of attending physician.

3.7.2.2 Exclusion Criteria

- Palliative Performance Scale level of 30% or less (Anderson et al., 1996), and
- Any person who, in the opinion of the treating physician, is within the last days to hours of life.

3.7.3 Sampling

I employed theoretical sampling as the purposeful process wherein the emerging theoretical framework determines where and what data to collect next (Bartlett & Payne, 1997). In keeping with classic grounded theory methods (Glaser, 1978), the process of sampling was conducted as seen in Figure 2:

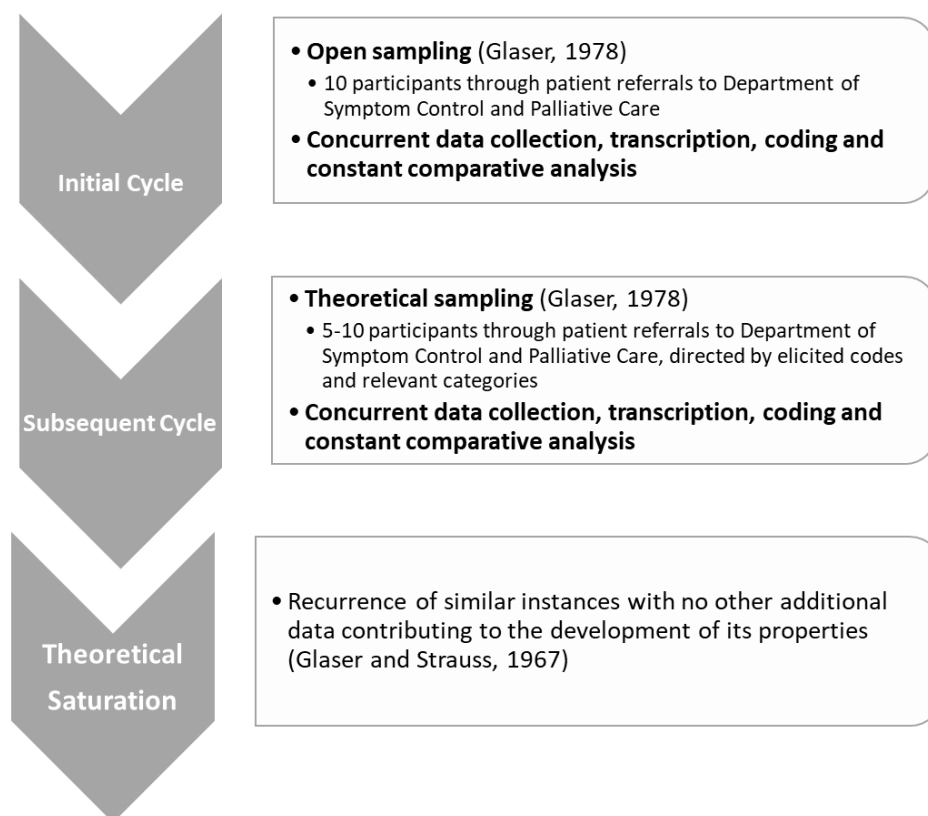


Figure 2. Flow Chart of Sampling for Study

My initial cycle of open sampling was guided only by a general understanding on where activity, the phenomenon of interest, resided (Glaser, 1978). As concurrent data collection, coding and analysis proceeded, the emerging theoretical framework directed me to what groups or subgroups I turned to next, in the subsequent cycle of theoretical sampling. Thus as theoretical sampling proceeded, it became more focused by collecting data to elaborate properties and dimensions of categories (Glaser & Strauss, 1967). The participant characteristics which guided theoretical sampling are reported as part of the study findings in Chapter Five.

Theoretical saturation was the criteria by which I decided to stop sampling different groups that were relevant to the core categories of the emerging theoretical framework, and which signifies the end of concurrent data collection, coding and analysis (Glaser & Strauss, 1967). According to classic grounded theory, theoretical saturation may be achieved for a

conceptual category if: a) diversity and range of data is maximized relevant to the conceptual category, b) any gaps within that category have been filled, and c) there is recurrence of similar instances with no other additional data contributing to the development of its properties (Glaser, 1978).

3.7.4 Study Recruitment

Ethical approval was obtained by all local institutional and Lancaster University review boards prior to study commencement (see Appendix A). Interdisciplinary team members from the Department of Symptom Control and Palliative Care screened all outpatient referrals for eligibility criteria for the study. When approaching potential participants for their verbal permission to contact them regarding the study, interdisciplinary team members provided my name to interested individuals, but did not disclose my medical background. Once the individual gave verbal permission for me to contact them regarding the study, I telephoned each potential participant and introduced myself as the researcher, and discussed the study in more detail. Following verbal approval to participate in the study, I faxed a letter to the participant's attending physician for their written approval for the individual to participate in the study (see Appendix B). After I received the attending physician's written approval, I then met face-to-face with each participant in order to obtain written informed consent (see Appendix C). Participants were assured that their clinical care would not be affected by participation in the study.

3.7.5 Data Collection

This was a two-phase, cross-sectional study, wherein output from an objective activity monitor and a daily record of symptoms (using a record sheet) were collected over seven days (Phase One). These were used in Phase Two as qualitative probes to gain in-depth understanding of the experience of activity in people with advanced cancer (see Figure 3):

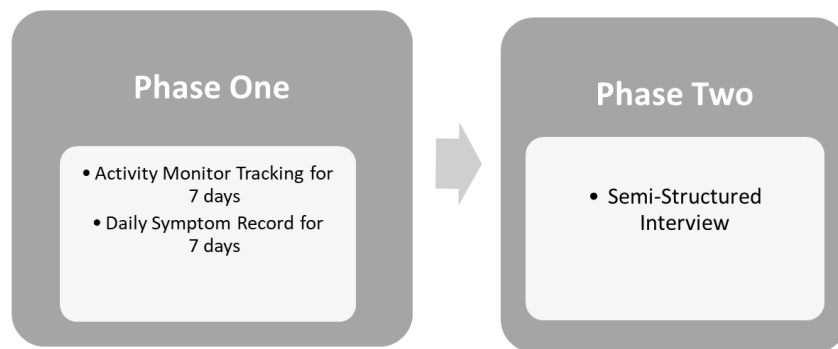


Figure 3. Flow Chart of Data Collection for Study

3.7.5.1 Phase One

For Phase One, participants wore an *activPAL*TM activity monitor (PAL Technologies Ltd, Glasgow, UK) to record free-living activity for seven days duration. The *activPAL*TM activity monitor is a 20 gram, 35 x 53 x 7 millimetre unit (see Image 1) that is secured to the participant's anterior mid-thigh using Cover-Roll[®] stretch adhesive fixation dressing (BSN Medical, Inc., Hamburg, Germany):



Image 1. The *activPAL*TM activity monitor placement on the researcher's leg

The *activPAL*TM system records triaxial movement and time spent supine, sitting, standing and stepping, including volume and intensity, on a second-by-second basis. The activity monitor has been validated in a number of clinical populations (Skipworth et al., 2011), and has been tested in people with thoracic cancer (Maddocks & Wilcock, 2012). From a positivist-empiricist perspective, objective activity monitors are considered the gold standard of quantitative measurement of physical activity in older adults (Gorman et al., 2014); from the subtle realist lens, it formed one of multiple means by which I sought to better understand the independent, tangible entity of activity in people with advanced cancer.

At the face-to-face meeting to obtain written informed consent, I explained the method of attachment and use of the *activPAL*TM activity monitor, and directly demonstrated this to the participant. Once the activity monitor was placed and secured, I gave the participant a one-week supply of adhesive dressing, and daily symptom record sheets for each day of the 7 day period. I asked participants to remove the units when bathing or showering, and replace once the underlying skin had dried.

At the end of each day during Phase One, participants filled out a single symptom record sheet. This documented their symptoms, how they felt, and general impressions of events for that day (see Appendix D). The daily record sheet included the revised Edmonton Symptom Assessment System (ESAS-r). The ESAS covers 9 items, including physical, psychological and well-being subscales, and has been also widely tested and validated in palliative care populations (Nekolaichuk, Watanabe, & Beaumont, 2008). I met with the participant at the end of the one-week period to collect the activity monitor and daily symptom record sheets.

3.7.5.2 Phase Two

Within one week of completing Phase One, I conducted face-to-face, semi-structured interviews with each participant. Participants were given the choice of location for their interview, either at their home (n=9) or at the tertiary cancer centre (n=6). Upon the participant's request, caregivers were allowed to be present during the interview, however I did not specifically elicit caregiver views. Each participant was interviewed once, with no repeat interviews. The interviews lasted from 39 minutes to 96 minutes, with a median interview time of 59 minutes. The activity monitor output (see Appendix E) and daily symptom record sheets were used as qualitative probes, by informing and individualizing interview questions to glean insight into what was relevant and significant from the participant's perspective (Payne, 2007). The semi-structured interview guide (see Appendix F) was supplemented with primary questions to cover the following topics: 1) participant's perceptions of activity, 2) participant's experiences of activity, and its meaning within the context of overall quality of life, and 3) participant's views on barriers and facilitators to activity. In keeping with the iterative nature of classic grounded theory method, interview questions changed and developed over time.

All interviews were recorded using a digital audio recorder (Speech Processing Solutions GmbH, Vienna, Austria). During and immediately after each interview, I wrote down my initial impressions and observations as field notes, which functioned as "in the moment reminders of incidents that may indicate potential concepts" (Holton & Walsh, 2017, p. 211). I did not solicit participant feedback on the interview transcripts, due to the limited life expectancy of participants. The activity monitor output was shared with the participants, and they were given the option to keep the printed activity monitor output at the conclusion of the interview.

Medical and demographic information about age, marital status, education, ethnicity, diagnosis, previous chemotherapy / radiotherapy, current medications, medical co-morbidities, current Palliative Performance Status level and date of death were collected via medical chart review. Gathering this information provided a context for participant responses.

3.7.6 Data Management

I transcribed the digital audio recordings after conducting each interview. The accuracy of all transcripts was checked against the original recordings, after which I made further notes and reflections. Transcripts were saved as Word documents, and initial codes and comments were made as line-by-line track changes, alongside the data. All data were thereafter uploaded onto ATLAS.ti™ qualitative data analysis software (ATLAS.ti™ Inc., Berlin, Germany) for ease of management of codes and conceptual memos, and to facilitate application of codes and memos across interview transcripts and activity monitor outputs (Frieze, 2016).

3.7.7 Data Analysis and Constant Comparative Technique

As per classic grounded theory methods (Glaser, 1978), I performed line-by-line, open codification on each interview transcript (see Appendix G), with integrated reference to my interview field notes, the participant's activity monitor output and daily symptom record. Preliminary codes were developed to group data together and encapsulate the main concepts emerging from the data. A conceptual category and its properties can emerge from a single case, which is one of multiple possible indicators for the generated concept. Similarities and differences can thus be compared between any groups that indicate the same conceptual categories, and their properties can then become significant qualifying conditions under which the categories exist and vary (Glaser & Strauss, 1967). Selective coding followed wherein only those factors that related to the emerging core category were analysed (Glaser, 1978).

I employed constant comparative analysis in order to generate conceptual categories, properties and hypotheses that were directly relevant to the emerging core category (Engward, 2013). Comparison of different slices of data shed new perspectives from which I was able to increase my theoretical understanding of the conceptual category, its properties and conditions. Constant comparative analysis was conducted concurrently, wherein emergent categories from early stages of data analysis informed subsequent data collection (Coyne, 1997). The emerging core concept thus guided my data collection and analysis in order to seek out the fullest diversity of categories, their properties and interrelationships (Engward, 2013).

In keeping with classic grounded theory, I wrote theoretical memos throughout coding and analysis, in order to elaborate conceptual categories, their properties and interrelationships, as well as to identify gaps. The conceptual and theoretical memos were printed and sorted by hand to facilitate emergence of conceptual categories, properties and dimensions, and ultimate integration of the theory (Glaser, 1992). This process leads to the delimitation of the theory's applicability, the broadening of its generality, and the increasing of its predictive and explanatory potential, all of which contribute to theoretical density and complexity. The step-by-step process of conceptualization using a categorical example is detailed in Chapter 4.

3.7.8 Study Rigour

In keeping with classic grounded theory methods (Glaser, 1978), I followed four main criteria for study rigour, including: a) *fit*, b) *understanding*, c) *generality*, and d) *control*. The *fit* of grounded theory pertains to its fidelity to the day-to-day reality of the substantive area under study; I increased the *fitness* of the theory by incorporating slices of data as diverse as possible through my use of theoretical sampling. *Understanding* refers to the ability to make sense of the theory as it relates to the phenomenon of interest; I increased the

understanding of the theory by iterative discussion of the emergent concepts with my supervisors and interdisciplinary colleagues throughout the analytic process. *Generality* pertains to the theory being conceptually abstract and broad enough in scope to be applicable to a wide range of contexts related to the phenomenon of interest; I increased the *generality* of the theory by applying constant comparative analytic technique between incident to incident, and concept to incident. *Control* pertains to the theory being dense in explication of conceptual categories, properties and interrelationships such that its conditions would be applicable to a specific situation; I increased the *control* of the theory by iterative memoing and hand-sorting of memos to achieve further integration of concepts and their interrelationships.

3.7.9 Ethical Considerations

People at the end of life may be viewed as a vulnerable research population, and hence their participation as research subjects may pose distinct ethical challenges (Hawryluck, 2004). Prior to study commencement, ethical approval was obtained by all local institutional and Lancaster University review boards (see Appendix A). The following ethical principles were addressed in this study: autonomy and non-maleficence.

3.7.9.1 Autonomy

The ethical principle of autonomy, which concerns the individual right to self-determination and respects the individual's ability to make informed decisions (Reyna, Bennett, & Bruera, 2007), was addressed in the study. By approaching potential participants and requesting their verbal permission for me to telephone them regarding the study, the interdisciplinary team members functioned as safeguards to the individual's rights (Reid, 2009). During my initial telephone call, and the subsequent face-to-face meeting with the potential participant, I discussed each and every aspect of the information sheet and consent form. The duration of at least 24 hours between the initial telephone call and face-to-face meeting

also gave potential participants sufficient time to consider involvement in the study. No coercion was used, and participants were reassured that their care would not be affected by their participation or non-participation in the study. All participants provided written informed consent (see Appendix C). The participants' attending physicians were also additional safeguards, as their written approval was obtained prior to study enrolment.

With respect to autonomy, the risk for power dynamic between the researcher and the participants (Riley, Schouten, & Cahill, 2003) was recognised and actions taken to mitigate it in this study. As a younger researcher interviewing older participants, and as a physician with training in clinical communication, I was sensitive to the risk of a power differential to the disadvantage of the participant. I addressed this by allowing participants to choose the location of the interview, and allowing participants the choice to be accompanied during the interview. I was careful not to impose the study on participants, when the timing was unsuitable, and I was flexible in scheduling the interviews. In my professional capacity as a physician, I had no clinical contact with participants before, during or after the study was conducted. When approaching potential participants for the study, the interdisciplinary team members did not disclose my professional background, and referred to me only as a PhD student. None of the participants asked me about my clinical background, and all participants appeared comfortable and expressed themselves freely during the interviews.

Confidentiality, a further element of autonomy which concerns the individual right to control the disclosure of one's own personal information (Reyna et al., 2007), was addressed by assuring participants that any information would only be used once identifying elements had been removed. Consent forms and the letter of written approval from the attending physicians, were the only pieces of data linking the participant's identity to the study. If participants chose to be interviewed at the tertiary cancer centre, every effort was made to secure a private space for the interview. During transcription, I maintained participant

anonymity and confidentiality by removing all identifying information. After transcription was completed and verified, the original digital audio recording was deleted.

To further mitigate the risk of a breach of confidentiality, all data were stored on a password-protected, encrypted computer. Study records were stored in a locked cabinet in a secure office at the tertiary cancer centre, with security features including monitored security system, smoke detectors and fire extinguishers. Only the researcher and supervisors will have access to the data. As per the Alberta Health Information Act (Alberta, 2016), study records will be kept for 25 years as per federal regulation, after which they will be shredded.

3.7.9.2 Non-Maleficence

Non-maleficence, which entails the researcher's duty to do no harm to the participant (Reyna et al., 2007), was addressed by informing participants during written informed consent, that they could stop and withdraw from the study at any time. During Phase One, participants were assured that if they perceived any difficulties with wearing the activity monitor, that they could stop its use at any time. No participants reported any difficulties with wearing the activity monitor, and all participants wore the activity monitor for the duration of Phase One. During the interview, discussion of end-of-life issues had the potential to cause emotional distress for the participant, and as part of the written consent form, each participant was provided with the contact information for the Department of Psychosocial and Spiritual Resources, for further support. Each participant was also provided with the contact information for the Alberta Health Services Patient Relations Department, in the event that the participant had any concerns about any aspect of the study or my conduct as the researcher. No participant asked to stop the interview or withdrew from the study.

3.8 Summary

Chapter 3 described how being personally and epistemologically reflexive led me to question the positivist-empiricist assumptions underlying my previous research. In order to explore the *emic* perspective of people with advanced cancer on participation in activity, a qualitative methodology was most appropriate. Subtle realism fit with my belief that activity exists as an independent reality that can only be accessed indirectly, and that may be examined through situational contingencies. Classic grounded theory methodology was most congruent with developing a new theoretical framework that aligns with the advanced cancer experience. To gain an in-depth understanding of the experience of activity in people with advanced cancer, a two-phase, cross-sectional, qualitative study was conducted through the post-positivist lens of subtle realism and informed by classic grounded theory methods. Using specific examples, the step-by-step process of conceptual development undertaken in this study will be explored in Chapter 4.

Chapter 4: The Process of Conceptual Development using Classic Grounded Theory Method

4.1 Introduction

Chapter 4 illustrates the step-by-step process of conceptual development undertaken in this study of activity in people with advanced cancer, using specific examples. According to Glaser (2001), classic grounded theory is built upon three levels of conceptual perspective analysis. Level one, data familiarisation, is considered in the first section, and the concept-indicator model is discussed. Next, the second level process, which includes core category emergence and constant comparative analysis to elaborate and saturate categories, is described. This chapter concludes by presenting the third level process of conceptual integration, using memoing and hand-sorting of memos. This chapter focuses on the emerging concepts of *responsibility* and *role as caregiver*, as exemplars of the tri-level conceptual perspective analysis. Given the word limitations of this thesis, providing the same level of detail for all emergent concepts was not possible; in practice, the same tri-level process was applied to the emergence and elaboration of each category in this study.

4.2 Data: The First Level of Conceptual Perspective Analysis

4.2.1 Data Familiarisation

In contradiction of Glaser's dictum (Glaser, 2001), I digitally recorded and transcribed all of the interviews myself. Glaser argues that the time required to listen to, type, review and correct interview transcripts is wasted, and that researchers should trust in their memory and preconscious processing of the participant encounter (Glaser, 2001). During my interviews, however, none of the participants displayed unease with the presence of the digital recorder, and from the depth and detail of their testimony, I believe that they shared

their experiences freely and without reservation. Glaser is correct in that transcription, in and of itself, delays the onset of substantive coding and analysis (in my study, this delay was approximately 6 months in total); thus data collection and analysis were not always concurrent. On the other hand, I feel that the process of actively listening to, transcribing and then reviewing interview recordings brought me closer to the data in a way that reinforced the groundedness of my subsequent coding and memoing. As a subtle realist, I acknowledge that transcription is not a neutral process, but at the same time, I do not endorse transcription as a means of co-constructing reality. In practice, transcription was another means through which I attempted to access a single independent reality of activity for these participants.

4.2.2 Data Coding and the Concept-Indicator Model

Following a classic grounded theory approach, my coding procedures were based upon the concept-indicator model (Glaser, 1978). A concept is “the naming of an emergent social pattern grounded in research data” (Glaser, 2002, p. 4), and is the result of higher level abstraction that emerges through the comparison of codes. Incidents, on the other hand, are “indicators of phenomena or experiences as observed or articulated in data” (Holton & Walsh, 2017, p. 212), and a single incident can be an indicator of more than one concept. A concept must earn its relevance into the emerging theoretical framework through constant comparison of incident to incident, followed by emerging concept to incident.

In keeping with the principles of classic grounded theory, I performed line-by-line coding of transcripts which integrated the physical activity patterns from the *activPAL*™ monitor output to what the participant identified as relevant during the interview (see Appendix G). I approached the data with the following three questions: 1) “what is the main concern of the study participant?” 2) “to what concept does this incident refer?”, and 3) “to what aspect of what concept does this incident refer?” (Glaser, 1998). By asking these three questions

regarding the participants' main concern and the concept being referenced, line-by-line analysis ensured relevance by generating codes that *fit* and were truly emergent (Holton, 2007).

Substantive codes were a direct result of fracturing the data using open and selective procedures (Holton, 2007). Open coding was the initial stage wherein I coded each incident in the data for as many relevant concepts as possible, and that yielded 352 substantive codes (see Appendix H). Through constant comparison of incident to incident, the concept of *responsibility* transcended the person, time and place of the specific incident, and gained conceptual generality. Thus the first level of conceptual perspective analysis is characterized by open coding and early memoing in support of the emergence of concepts. The following example illustrates the emergence of the concept of *responsibility*. This excerpt from the ACT04 interview transcript depicted a specific incident (i.e. discussion of housework) which functioned as one indicator of *responsibility*. The participant quotation is used to illustrate the emerging concept, and the subsequent early memo reflects my questions that arose upon interrogating the data.

Data from Field Interview ACT04, May 7, 2014

Well, nobody else will do them [getting breakfast ready, making your bed, putting the clothes in the wash]. Well I have to.

Memo: Sole Provider, August 22, 2014

ACT04 does these activities because she is the primary caregiver and they need to be done, she is the only one to be able to do them

ACT04 identifies her minimum level of responsibility that needs to be met – in her case, engaging in the instrumental activities of daily living for both her spouse and herself - how does this vary between participants?

4.3 Category: The Second Level of Conceptual Perspective Analysis

4.3.1 *The Core Conceptual Category*

Using a classic grounded theory approach, I examined concepts as data in order to abstract to a higher level of conceptualization. A category is a higher level concept that encapsulates the latent patterns present in the data. Properties are a category's latent characteristics that are not directly measurable, and dimensions are measurable components that are complementary to define a category (Glaser, 2002). A core conceptual category distinguishes itself by the following characteristics: 1) it is central in its relationship to other categories and their properties, and 2) it explains a large degree of variation in the behaviour of participants (Glaser, 1978).

Through constant comparison of incidents within the data, *maintaining responsibility* emerged as the participant's main concern, and the *critical threshold* of responsibility emerged as a potential core category in September 2014. The category of *critical threshold* seemed to encompass the multivariate processing of the day-to-day experiences of participants as revealed through their interviews, as well as the diversity in physical activity patterns as identified through *activPAL™* monitoring. Thus the *critical threshold* became the core conceptual category from which further theoretical sampling was planned, starting in November 2014, to pursue the sub-categories of the *critical threshold*. The ensuing transition from open to selective coding was then focused upon developing the properties and dimensions of the sub-categories of the *critical threshold*, and subsequent codes delimited to 42 unique code families (see Appendix I).

4.3.2 *Constant Comparative Analysis*

In keeping with the principles of classic grounded theory, I applied the constant comparative method of analysis to the data, incidents, concepts and categories. Constant comparison fulfils the following functions: 1) it lends validity to the concept as a category which

represents a latent pattern in the data, 2) it lends reliability to the category and its *fit* with the latent pattern that it represents, 3) it produces dimensions and properties of the category, and 4) through the interchangeability of indicators, the category and its properties achieve saturation (Glaser, 2001). I therefore utilized constant comparison to find evidence in the data in support of the core conceptual category of *critical threshold*, to substantiate its emergence, and to further elaborate upon its dimensions and properties. The ACT10 interview transcript depicted a specific incident (i.e. caring for pet) which functioned as one indicator of *responsibility*. Additional incidents, such as the following quotation excerpted from the ACT10 interview transcript, were compared against previous incidents, and then compared to the emerging core category of *critical threshold* itself.

Data from Field Interview ACT10, May 22, 2014

I've wanted him for, I've wanted a dog for a long time, and nobody in my family seemed to get why, you know, and I mean it helps, like, it helps with that sense of purpose...

Memo: Acquiring New Responsibility, August 30, 2014

ACT10 relating her desire to care for a dog to her desire to care for others, to contribute to the well-being of others, even though she cannot work at her previous job, she recognizes the need to have a purpose in her life

Acquiring a new responsibility in full knowledge of the palliative stage of her disease – what factors contribute to this choice?

I employed selective coding to further delimit to what was relevant to the core conceptual category, and to build upon its dimensions and properties (Holton, 2007). Glaser (2001) refers to the selective coding stage as the saturation of concepts and their properties, in conjunction with theoretical sampling. Continued coding and analysis yielded further linkages between the core conceptual category, its sub-categories and dimensions. Indicators, such as the following excerpt from the ACT11 interview transcript, were

interchangeable in their illustration of the *critical threshold*, yet they highlighted different dimensions of the core variable.

Data from Interview ACT11, December 4, 2014

ACT11: Yeah, yeah, that's always been a big one with me, Mom and I have always been very close, [clears throat], she lived with me for about 4 years, but we're temperaments are too, um, we can't live together under the same roof because we'll kill each other. [laughter] But you know, as long as we have our separate time, then we get along just fine, yeah. So we talk to each other every single day on the phone, you know, and then, or text or whatever, um but a day doesn't go by without talking.

Researcher: Do you feel that she is dependent on you, in some ways?

ACT11: She is a little bit, but I've worked hard at getting that so it's not that way [breaking down into tears]. I don't want her to [pause] have to hard a time when I go. [crying] I worry about her, that's all. Sorry.[pause] But my other sisters and brothers have picked up, because it used to be just me all the time, right? And but, she came down with colon cancer too...Then they started spending their time with her, and taking her out shopping and doing things with her, and um, that got a little bit easier that way, so I didn't have to as much. So now, so now she's really good, she spends time with me without expecting me to spend time with her, so it's better that way.

Memo: Nature of the Caregiving Relationship, February 20, 2015

The nature of the caregiving relationship appears to depend on the subject of caregiving. For ACT11, it was being the primary support for her elderly mother - a role that she is passing onto her siblings in preparation for the future. Also for ACT11, she was helping to care for grandchildren - picking one up from school and driving him to his employment, and also caring for the other at home. Responsibilities such as these appear to be transferable - ACT11 does not want her elderly mother to become too reliant on her because she knows that her time is short, and so she delegates to her siblings, but she appreciates the meaningful time with her. ACT11 helps out with her grandchildren while she can, to spend meaningful time with them.

The responsibility remains but its nature changes over time as the subject of caregiving grows and becomes more independent. In that respect it is more of maintaining the meaningful relationship between the caregiver and one being cared for?

Through constant comparative analysis and interchangeability of indicators, I found that subsequent incidents failed to yield any new ideation, and the core concept and its related

categories were sufficiently saturated. This marked the transition from substantive coding to theoretical coding, and the onset of conceptual integration using theoretical memos.

4.4 Memo: The Third Level of Conceptual Perspective Analysis

The third level of conceptual perspective analysis involves memoing, which is defined as the “core ideational processing of theoretical ideas as they emerge through coding and constant comparative analysis” (Holton & Walsh, 2017, p. 212). My memos were free form notes about the data and offered hypotheses about potential connections between categories, properties and dimensions. I wrote memos concurrently with open coding all the way through to integration of the emergent theoretical framework. My early memos were “works in progress, intended to capture ideas as they emerge without the worries of writing style, grammar, and spelling” (Holton & Walsh, 2017, p. 91). Later, more substantial memos begin to integrate theoretical connections between categories in order to generate a theoretical framework. A total of 238 memos were created over the course of this study (see Appendix J).

The following traces the chronological journey of the conceptual development of *role as caregiver*. 38 specific indicators of the concept of *role as caregiver* appeared in interview data between April 2014 to January 2015. In keeping with classic grounded theory, concepts were developed through constant comparison of indicators and concurrent memoing to expand upon emergent properties and dimensions of the concept. An iterative process of memoing occurred throughout data collection and analysis. Between September 2014 to December 2015, 12 memos on the concept of *role as caregiver* were written; early memos were characterized by initial thoughts and questions that arose from the data, whereas later, more mature memos were characterized by the forging of more detailed connections across indicators and between concepts. The concept of *role as caregiver* appeared in open coding of interview data (Interviews with ACT04, ACT06, ACT07, ACT09, ACT10, ACT11,

ACT12, ACT13, ACT14, ACT15). The following excerpts from the ACT04 and ACT07 interview transcripts illustrate how early memos questioned delegating, transferring, and person support as related to the concept of *role as caregiver*:

Data from Interview ACT04, May 7, 2014

I've been put on morphine, and the pain just got worse, and they'd up the morphine, and the pain just got worse, and they'd up the morphine again, and I was you know at 15mg a day, and I was just out of it, and sleeping all day and poor [spouse] sat in his chair and I was barely able to get us something to eat, and I just thought, hey, I can't live like this... So I figured it was better to have pain and have my head straight, and I just stopped cold turkey.

Memo: Caregiving, September 15, 2014

Is caregiving a critical responsibility (one that is on the onus of the participant to fulfill)?

Does critical responsibility vary from individual to individual, or are there certain core critical responsibilities that stay the same across individuals?

Does it matter if different individuals see responsibility differently?

Delegating the primary care of spouse or loved ones: temporary versus permanent?

What people or processes can I have in place to care for spouse or loved ones even when I am not present?

Making sure spouse or loved one's basic needs are met: food, water, shelter, but also guarding against potential health complications on the part of the spouse or loved one

Is caregiving always self-sacrificing on the part of the caregiver? How does this change at the end stage of cancer?

Data from Interview ACT07, May 8, 2014

INT: And, when you walk the dog outside, do you find that it's a strenuous activity for you?

ACT07: Uh, just getting up out of a chair is pretty strenuous, yeah. But uh, the dog's enthusiastic, you know...A little 6 year old kid could do the same thing and have no trouble, you know.

Memo: Caregiver Spouse, October 9, 2014

ACT07 was being cared for by his spouse, who did the majority of the talking during their interview - ACT07 did enjoy caring for their pets, but he had a spouse who took primary responsibility for his instrumental activities of daily living. Wondering if this links to his response that being active or not was not a primary concern for him - if his spouse was taking primary responsibility for day-to-day care, then he would not need activity if he did not have to resolve a concern. He did, however, engage in activity related to caring for his pet - scooping the poop, walking the pet around the cul-de-sac - so fulfilling this responsibility gives him fulfillment because of the relationship with the animal?

Iterative theoretical memoing facilitated the emergence of additional properties of the *role of caregiver*, as analysis proceeded. The role of caregiver is linked to the core conceptual category of the *critical threshold*.

Data from Interview ACT10, May 22, 2014

And then taking my dog out at 5AM would be accurate, because if I went to bed around that time, I take him out every 4.5 hours or so, so that would be taking him out again...just the balcony, he's too small to go [outdoors by himself], yeah, and for me it's hard to get up and down the stairs, so.

Memo: Caregiving pets, November 11, 2014

Three-month old dog is always in close proximity to her, completely dependent on her.

Awakens in the middle of the night to take dog out to the balcony, too difficult for her to go down and up stairs to the outside of building, and no elevator.

Dog does best when he is sitting with her.

Attends to his needs first thing in the morning, takes him out to balcony, then goes to sit on the couch to rest, then leaves him to get organized.

Organizes dog first, then gets up to do her own tasks that need to be done.

Employed as child and youth care counsellor for local youth centre - caregiving as part of her job.

Getting the dog one month ago helped her to be more mobile and active.

Caring for dog helps her with having a sense of purpose, caring for someone - but it's not enough.

Passionate about job caring for kids and youth, and misses working with them.

For caregivers of pets, it can be the unconditional love and affection which animals can display towards their carers - unlike children, pets do not become more independent of owners as they age, and still require the same amount of care. But these are duties that become quite central to participants' activities, such as ACT07 whose sole daily activity is walking and looking after his pet, but which spouse confirms gives him great joy.

This responsibility is also taken very seriously by ACT10 and her desire to care for her tiny dog who cannot care for himself.

Theoretical sampling should examine different incidents of caregiving subjects: 1) pets, 2) spouses, 3) young children, 4) adult children, 5) parents?

Later, theoretical memos illustrated how connections begin to be forged within the emerging theoretical framework. The following memo was sparked by my one-on-one conversation with Dr. Glaser at the 2015 Grounded Theory Institute:

Memo: Maintaining Responsibility, May 30, 2015

After my conversation with Dr. Glaser, I'm beginning to see my study in a new light: that of *maintaining responsibility* in the substantive area of end stage cancer. Downsizing reflects how participants address the main concern of *maintaining responsibility*, by adjusting the *critical threshold* that must be met to the fluctuating intensity and frequency of symptom burden. Dr. Glaser re-iterated today that my professional interest in physical activity is not the same as the participants' concern: it is becoming clearer to me that day-to-day activity is just a mechanism by which participants address their main concern of *maintaining responsibility*, no matter how small. Hence my core categorical nomenclature of *activity as responsibility* needs to be amended; *maintaining responsibility* is the main concern and the *critical threshold of responsibility* is the core conceptual category. Making this connection feels grounded in the data, and has "grab" for me.

Based on preliminary suggestions from the Grounded Theory Institute seminar group, I am needing to go back and do more theoretical memos on the dimensions of the core conceptual category including caring for dependents, mentoring, sole provider, affirming bonds and restoration of self, as well as the properties of purpose/contribution, sense of meaning and respecting limitations. Some of these may need to be collapsed through further theoretical memoing, and new ones may emerge by going back through data from the initial open sample. I am beginning to glimpse the overall conceptual framework from which I can build the theory.

Once theoretical saturation was achieved, I reviewed and hand-sorted memos with respect to the core conceptual category, related categories, and their inter-relationships. Hand-sorting of memos enabled me to consider similarities, differences and ordering between categories, and sparked further memos from which putative connections between categories were integrated. Hand-sorting of memos thus yields a nascent framework of theoretical propositions, which delineates the nature of relationships between concepts that emerged from empirical data (Glaser, 1978). This emergent theoretical framework will be presented in Chapters 5 and 6.

4.5 Summary

Chapter 4 detailed the step-by-step, tri-level process of conceptual development undertaken in this study of activity in people with advanced cancer, using specific examples. The first

level involved data familiarisation and open coding using the concept-indicator model. The second level included the emergence of the core conceptual category, and constant comparative analysis to elaborate upon its properties and dimensions. The third level was comprised of memoing and the hand-sorting of memos, which facilitated theoretical integration of the core conceptual category, related categories, and their interrelationships. This tri-level process of conceptual perspective analysis was applied to the emergence and elaboration of each category in the study. The end product of this analytic process is the emergent theoretical framework, which will be presented in Chapters 5 and 6.

Chapter 5 - The Emergent Theoretical Framework: The Main Concern and Core Conceptual Category

5.1 Introduction

Together, Chapters 5 and 6 present the emergent theoretical framework of conceptual relationships which explain the underlying pattern of behaviour of people with advanced cancer. Chapter 5 introduces the participants' main concern and the core conceptual category as the central components of the emergent theoretical framework. Chapter 6 will then build upon this foundation by describing the dimensions and properties of related categories, which in turn explains the large degree of variation in the behaviour of participants. The literature review in Chapter 7 will provide further data for the development of the emergent theoretical framework, and Chapter 8 will present the final grounded theory.

Chapter 5 begins by briefly reporting the study participants' characteristics. This chapter first considers the participants' main concern, or the issue that occupies much of their behaviour and attention in the area under study (Holton & Walsh, 2017). Chapter 5 then examines the core conceptual category as the primary variable which accounts for how the main concern is managed; the core conceptual category is central in its relationship to other categories and their properties (Holton & Walsh, 2017). Chapter 5 then introduces the decision-making strategy by which participants manage their main concern. Each concept of the emergent theoretical framework is addressed in separate sections of this chapter. Direct participant quotations are used to illustrate each concept. All study participants, each of whom is identified by the letters "ACT" and a number (1-15), are represented in Chapters 5 and 6.

5.1.1 Study Participant Characteristics

15 people with advanced cancer participated in the study; six males and nine females. All participants were Caucasian. They ranged in age from 23-85 years old, with a median age of

67 years old. The most common cancer primary was gastrointestinal (n=4), followed by lung (n=2), breast (n=2), cervix (n=2), genitourinary (n=1), melanoma (n=1), lymphoma (n=1), parotid gland (n=1) and peritoneum (n=1). At the time of study entry, the majority of participants (n=8) were not undergoing any treatment; five participants were undergoing palliative chemotherapy, and two participants were undergoing palliative radiotherapy. The median number of steps taken per day by participants was 1625, and the median ESAS symptom distress score of participants was 20. As of March 2017, all study participants were deceased, with a median survival of 100 days from date of study entry to date of death. The maximum duration from time of study entry to time of death was 637 days, and the minimum duration was 20 days.

From March to June 2014, 10 people with advanced cancer participated in the initial cycle of open sampling. As described in section 3.73 of Chapter 3, the initial cycle of open sampling gained full coverage of people with advanced cancer, as conceptual categories begin to emerge. Participant characteristics from the initial cycle of open sampling are described in Table 1.

Table 1. Participant Characteristics from Initial Cycle of Open Sampling

Participant	Gender	Age (years)	Cancer Primary	Current Treatment	Members Present at Interview	Survival from Date of Study Entry (days)	Median Number of Steps per Day (steps)	Median ESAS Symptom Distress Score
ACT01	Male	75	Oesophagus	Palliative Radiotherapy	Spouse	66	780	26
ACT02	Male	85	Kidney	None	Spouse	127	3444	31
ACT03	Female	75	Lung	None	Son and Friend	100	2540	24
ACT04	Female	74	Lung	Palliative Chemotherapy	Spouse	637	2706	19.5
ACT05	Male	67	Colon	None	None	258	460	8.5
ACT06	Female	68	Melanoma	None	Spouse	20	624	15.5
ACT07	Male	82	Lymphoma	None	Spouse	40	1427	20
ACT08	Male	39	Parotid Gland	Palliative Chemotherapy	None	80	238	17.5
ACT09	Female	78	Peritoneum	None	Spouse	309	1543	34
ACT10	Female	23	Cervix	Palliative Chemotherapy	None	239	1627	32

As concurrent data collection, coding and analysis proceeded, the emergent core category directed the subgroups of interest for the selective cycle of theoretical sampling. As detailed in section 3.73 of Chapter 3, theoretical sampling thus became more focused, by collecting data for the elaboration of properties and dimensions of emergent concepts. From October 2014 to January 2015, 5 people with advanced cancer participated in the selective cycle of theoretical sampling. Participants from the subsequent cycle of theoretical sampling are described in Table 2.

Table 2. Participant Characteristics from Subsequent Cycle of Theoretical Sampling

Participant	Gender	Age (years)	Cancer Primary	Current Treatment	Members Present at Interview	Survival from Date of Study Entry (days)	Characteristics of Interest for Theoretical Sampling	Median Number of Steps per Day (steps)	Median ESAS Symptom Distress Score
ACT11	Female	55	Colon	None	None	94	Role of Grandparent No Partner Not Employed	6521	6
ACT12	Female	23	Breast	Palliative Chemotherapy	Mother	129	Role of Adult Child No Partner Not Employed	2868	20
ACT13	Male	53	Pancreas	None	Spouse	32	Role of Spouse Employed	1363	24.5
ACT14	Female	53	Cervix	Palliative Radiotherapy	Partner	127	Role of Partner Self-Employed	1751	36
ACT15	Female	58	Breast	Palliative Chemotherapy	None	72	Role of Parent No Partner Employed Role of Volunteer	4030	20

By October 2015, concurrent coding and constant comparative analysis revealed that: a) the range of data were maximized relevant to the emergent core category, b) the initial gaps within the core category were filled, and c) there was recurrence of similar instances with no other additional data contributing to the development of the core category's properties. Thus theoretical saturation was achieved in keeping with a classic grounded theory approach.

5.2 The Main Concern: *Maintaining Responsibility*

In this study of activity in people with advanced cancer, *maintaining responsibility* emerged as the main concern uniting all participant experiences. Responsibilities are viewed as duties or tasks which are incumbent upon the participant to fulfil. Responsibilities are specific to each person with advanced cancer, and can be held throughout the course of life. The length of time that a responsibility is previously held, however, does not necessarily lend itself to being prioritized at the end of life. Understanding of disease and its prognosis impacts the choice of particular obligations to which people with advanced cancer devote their limited time and energy.

ACT14: [pause] That's life, that's part of life. It's, it's the life code, it's [pause] you have family, you help your family. You open up a business, it's your responsibility to keep it running. If you have pets, they're your responsibilities to take over. If you have children, it's your responsibility to raise them properly.

Disease progression, fluctuant symptom burden and functional decline compromise the ability of people with advanced cancer to manage their main concern. *Maintaining responsibility*, no matter how small, can yield an increased feeling of contribution despite these challenges. People with advanced cancer do the best for their ability and for the time that they have remaining. Doing a little bit is preferable to doing nothing at all.

ACT14: *Yes, whatever I do in that home is important right now, yeah, because I still am going to try to do a few little tasks, while I'm there, and while I'm at home, there are tasks that I still can do...Every little bit counts.*

5.3 The Core Conceptual Category: *Critical Threshold*

The *critical threshold* emerged as the core conceptual category in this study of activity in people with advanced cancer. The *critical threshold* is viewed as the minimum level of responsibility to be met at that point in time, and is uniquely defined by each participant. The ability of participants to do even small tasks is challenged by disease progression and symptom burden, and thus the *critical threshold* changes towards the end of life. The person with advanced cancer can endure increased symptoms in order to meet the *critical threshold*. Even when a task cannot be completed independently, there can still be ways to feasibly meet the minimum level of responsibility. People with advanced cancer perceive those necessary aspects that are required to meet the *critical threshold*.

ACT15: *I don't think I would have done any necessarily more or less...but in general I just did what needed to be done, right?*

Three distinct sub-categories of the *critical threshold* emerged from this study of activity in people with advanced cancer: *provision for self*, *key relations* and *commitment to community* (see Figure 4). In practice, the degree to which the *critical threshold* encompasses these three sub-categories is unique to each person with advanced cancer. In the following sections, an overview of each sub-category, and its associated dimensions and properties, is provided. *Provision for self* is discussed first, then *key relations*, and finally *commitment to community*.

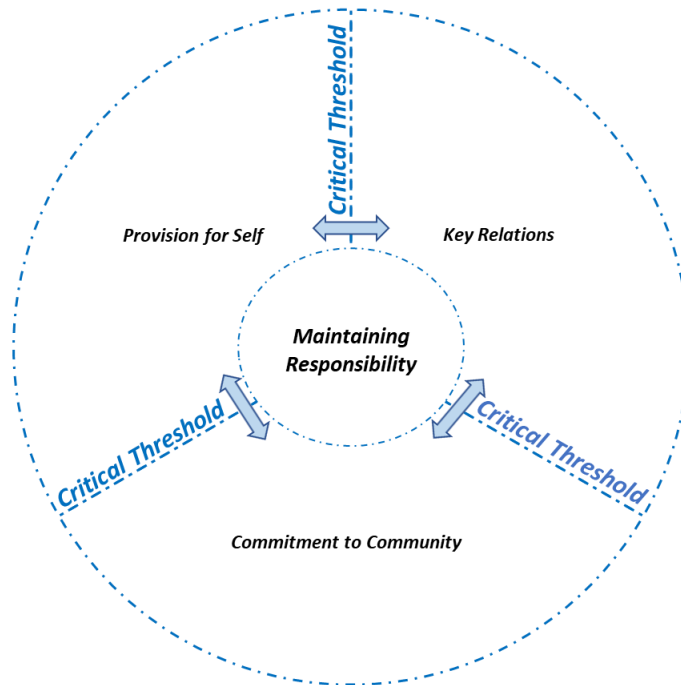


Figure 4: The Sub-Categories of the *Critical Threshold*: *Provision for Self*, *Key Relations* and *Commitment to Community*

5.3.1 *Provision for Self*: A Sub-Category of the *Critical Threshold*

Provision for self, the first sub-category of the *critical threshold*, is viewed as doing what is needed to exist. For people with advanced cancer, this relates to the tasks and duties associated with the day-to-day care of one's physical, psychosocial and spiritual well-being. *Provision for self* includes people with advanced cancer coordinating and conducting obligations for their own well-being and health needs. Depending upon day-to-day fluctuations and symptom burden, the person with advanced cancer can prioritize *provision for self* as the most important obligation to be fulfilled at any given moment.

Three separate dimensions of *provision for self* emerged: *self-care*, *self-management of health*, and *self-sufficiency* (see Figure 5). Each dimension is independent of the others with respect to *provision for self*, and the person with advanced cancer can address one or more of these dimensions in order to meet the *critical threshold*. In the following sub-sections, *self-care* is discussed first, then *self-management of health*, and finally *self-sufficiency*.

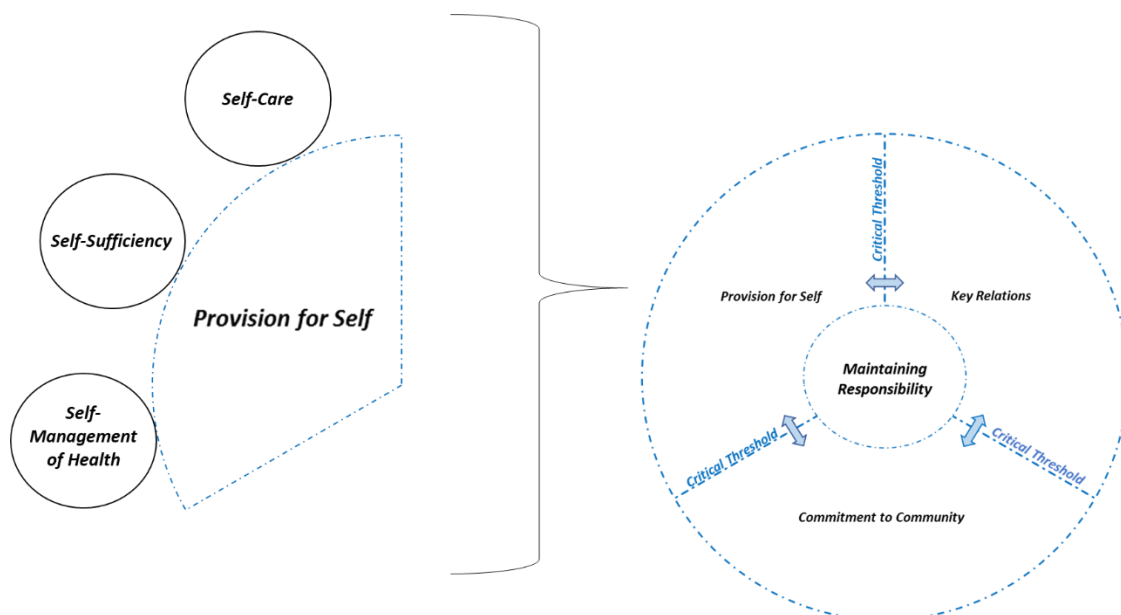


Figure 5: The Dimensions of *Provision for Self*: *Self-Care*, *Self-Management of Health* and *Self-Sufficiency*

5.3.1.1 Self-Care

Self-care, or the obligation to care for oneself, is the first dimension of *provision for self*. The participant's ability to manage *self-care* is a prerequisite to the ability to meet all other obligations. Personal safety considerations, and minimizing the risk of bodily harm or injury, can take precedence in times of high symptom burden. People with advanced cancer focus on getting by one day at a time.

ACT10: yeah I think right now I feel like I'm just surviving, you're not really living, not doing things, you're just surviving, that's it.

Two unique properties of *self-care* emerged from this study of activity in people with advanced cancer: *symptom control* and *respect for limitations* (see Figure 6). The first property of *self-care* is *symptom control*, which is viewed as the alleviation of symptoms by use of medication, treatments (i.e. palliative chemotherapy, palliative radiotherapy or palliative procedures) or behavioural techniques (i.e. positional changes or movements) in order to reduce suffering. Precautionary measures can be taken to avoid positions or

behaviour which aggravate symptoms. Alleviating symptoms, such as poorly controlled pain, can take precedence before all other responsibilities.

ACT10: I guess to just get rid of this pain, like number one the pain, you know, living like, you can live with the cancer, you know, but it's the pain that gets you, right? Living with the cancer sucks as it is, but at least [by treating the pain] you can move around and do stuff and kind of forget about it or, not forget about it but live, you know.

The second property of *self-care* is *respect for limitations*. *Respect for limitations* is viewed as the awareness of potential barriers to meeting the *critical threshold*. Barriers can be compounded by symptom burden and functional decline. The participant's awareness includes listening to one's body and trusting one's intuition regarding the same. People with advanced cancer evaluate prevailing conditions and draw upon previous experience to determine individual boundaries. Pushing beyond these boundaries can compromise the ability to meet the *critical threshold*, and increase frustration. Awareness of stress levels can lead to refraining from placing unnecessary pressure on oneself.

ACT09: But sometimes my body just says sleep, and I do it, at this stage, stage 4, I think you need to listen to that too, and not worry about the time of day or anything, you know.

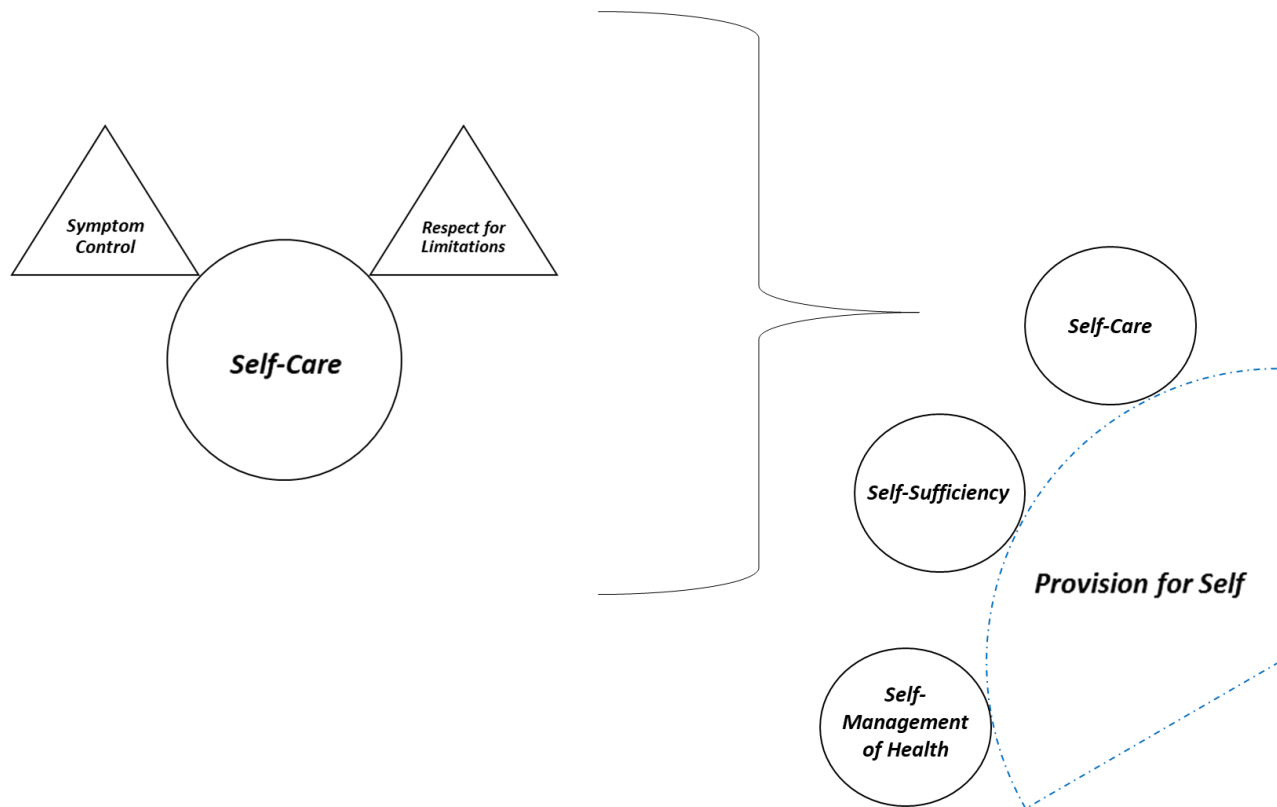


Figure 6: The Properties of *Self-Care*: *Symptom Control* and *Respect for Limitations*

5.3.1.2 *Self-Management of Health*

Self-management of health is the second dimension of *provision for self*. *Self-management of health* is viewed as being accountable and advocating for personal well-being. This includes evaluation of health professionals' advice, and weighing the advantages and disadvantages of diet, medication and treatment options. People with advanced cancer are willing to tolerate medication- or treatment-related sequelae if the potential for symptom relief is great. A decision to forgo treatment, on the other hand, is meaningful in the context of disease progression. A supportive relationship with the health care team is vital to *self-management of health*. Fostering psychosocial and spiritual well-being include giving oneself permission, time and space to cope with intense emotions.

ACT04: I'm just trying to look after myself as best as I can, and then not getting too tired and uh you know one of the first things they said...was you know, not to have

stress in your life, and that's what I'm trying to do, so if I have to lie down and have a snooze, I do.

5.3.1.3 Self-Sufficiency

Self-sufficiency is the third dimension of *provision for self*. *Self-sufficiency* is viewed as being able to manage independently, without being a burden on others. Disease progression, symptom fluctuations and functional limitations can compromise *self-sufficiency*. Even if the tasks are small or modified, people with advanced cancer value the ability to do things independently as much as possible. *Self-sufficiency* includes making changes in living circumstances, and accessing support from others in order to meet the *critical threshold*.

ACT09: being able to fend for myself as much as possible...I mean I realize I can't do everything anymore, and that's hard to take, but I'm getting used to that.

5.3.2 Key Relations

The second sub-category of the *critical threshold*, *key relations*, comprises the responsibilities which people with advanced cancer assume within their households and families. These are associated with roles acquired through marriage or birth, or that were initiated with others over time. People with advanced cancer seek to minimize burden on family members and loved ones. At times, the needs of others can be prioritized over personal well-being. Open communication, emotional connection and social contact are valued.

ACT11: But now I'm doing my best to make sure everybody has time... whereas it wasn't so important before, right? But now I'm making sure that everybody has time, yeah.

Five different dimensions of *key relations* emerged from this study of activity in people with advanced cancer: *role of caregiver*, *role of spouse*, *role of parent*, *role of adult child*, and *role*

of grandparent (see Figure 7). Each dimension is independent of the others with respect to *key relations*, and the person with advanced cancer can address one or more of these dimensions in order to meet the *critical threshold*. In the following sub-sections, *role of caregiver* is discussed first, then *role of spouse*, *role of parent*, *role of adult child*, and finally *role of grandparent*.

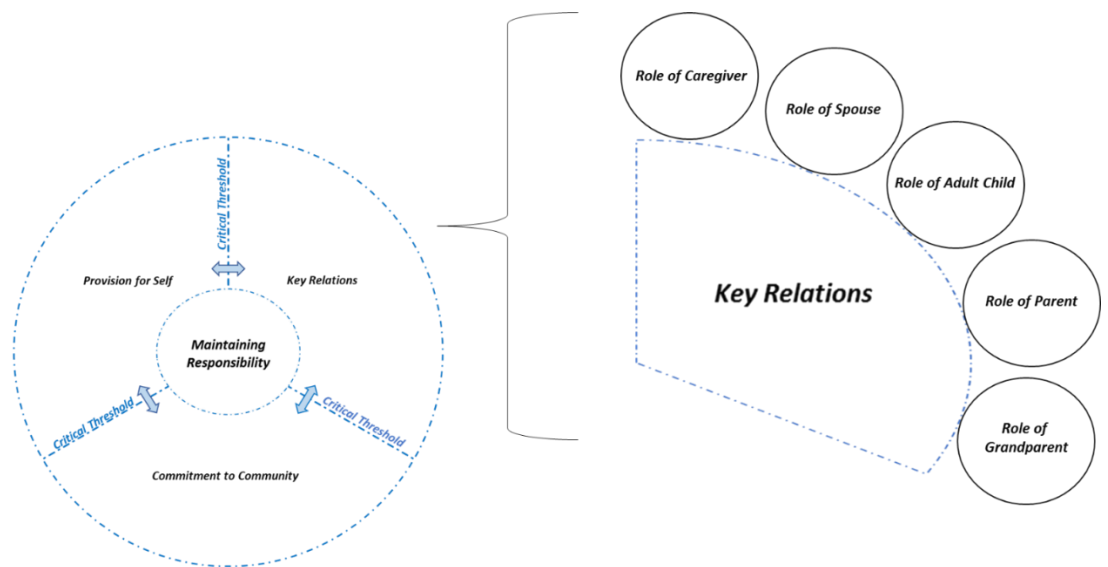


Figure 7: The Dimensions of *Key Relations*: *Role of Caregiver*, *Role of Spouse*, *Role of Adult Child*, *Role of Parent*, and *Role of Grandparent*

5.3.2.1 *Role of Caregiver*

The first dimension of *key relations* is the *role of caregiver*, which is viewed as responsibility for the welfare of dependents. This includes ensuring that the dependent's basic needs are met, and guarding against risks to the dependent's safety and health. Those who are completely dependent for their basic needs, such as pets, can be central to the participant's daily routine. Attending to the needs of dependents can aggravate the participant's symptom burden. As a sole caregiver, the person with advanced cancer can prioritize the care of dependents over their own personal well-being.

ACT10: Because if I went to bed around that time, I take the dog out every 4.5 hours or so, so that would be taking him out again, just to the balcony, he's too small to go [outside by himself], yeah, and for me it's hard to get up and down the stairs, so...it's getting better, but, yeah he's too tiny to, he just goes on the balcony. You saw him.

5.3.2.2 Role of Spouse

The second dimension of *key relations* is the *role of spouse*. If the spouse is the primary caregiver, they may alleviate the burden of *self-care* and *self-management of health* from the person with advanced cancer. In contrast, if the person with advanced cancer is the caregiver of an elderly or infirm spouse, one can align daily routine to the needs of the spouse. Anticipatory planning form part of this dimension, where supports are put in place for the spouse when the participant has died or is absent.

ACT04: I would like to [do more activity], but uh, [her spouse] has had a couple of bouts with you know, sort of, passing out or small TIA or something, and I don't like to leave him alone, so if I'm going out, then I want to have somebody here with him.

5.3.2.3 Role of Parent

The third dimension of *key relations* is the *role of parent*. Towards young children, this responsibility includes imparting values and providing hands-on support, ranging from fulfilment of basic needs to fostering independence. Towards adult children, this responsibility includes upholding traditions, and providing mentorship and emotional support. People with advanced cancer seek to minimize burden on their children, and to strengthen familial bonds. Preparing children for potential outcomes of progressive disease, and alleviating suffering from anticipatory loss, are valued towards the end of life.

ACT06: it's coming quicker than we thought, but that's all I can really do is sort of reassure them, that life will go on for them, and it is as it is. That's basically all I can

offer I guess at this point, I think. It's not a lot of reassurance or anything, but I think it's what I can offer them as their parent.

5.3.2.4 Role of Adult Child

The fourth dimension of *key relations* is the *role of adult child*. This responsibility to care for elderly or infirm parents can be prioritized over personal well-being. The parent can provide increasing assistance to the person with advanced cancer with the dimension of *self-care*, as the disease progresses and function declines. Putting supports in place and preparing a smooth transition for parents is meaningful, in view of the participant's eventual passing.

ACT11. [My mother] is [dependent on me], but I've worked hard at getting that so it's not that way. I don't want her to [pause] have too hard a time when I go...she spends time with me without expecting me to spend time with her, so it's better that way.

5.3.2.5 Role of Grandparent

The final dimension of *key relations* is the *role of grandparent*. This responsibility includes preparing grandchildren for potential outcomes, and trying to minimize suffering in anticipation of the participant's eventual death. Making positive memories and sharing traditions reinforce familial bonds across generations. Providing information, opportunities to ask questions, and emotional support to grandchildren is an important component of this transition.

ACT11: at one point we were walking in the yard, and she was holding my hand, and she looked at me and she says "Nanny", she says, "I know you have to go to heaven" but she said "I don't want you to go today." So...they're working their way through it, yeah [pause]. But it's not something that I'm hiding even from them.

5.3.3 Commitment to Community

The final sub-category of the *critical threshold, commitment to community*, is detailed in this section. *Commitment to community* are the responsibilities which people with advanced cancer assume with regards to their vocation and to society. People with advanced cancer view vocation as their line of work or profession; they view society as volunteering or assuming leadership in community organisations. Symptom fluctuation and medication- and treatment-related sequelae could necessitate modifications in tasks related to these responsibilities. Despite disease progression and functional decline, the person with advanced cancer values being able to contribute towards one's household and community.

ACT15: And I do a lot of volunteer things too, they're also extremely important to me, so. Um, so that's another thing that people are telling me: "drop that stuff, drop that stuff".

Two separate dimensions of *commitment to community* emerged from this study of activity in people with advanced cancer: *vocation* and *society* (see Figure 8). The person with advanced cancer can address one or more of these dimensions of *commitment to community*, in order to meet the *critical threshold*. In the following sub-sections, *vocation* is discussed first, followed by *society*.

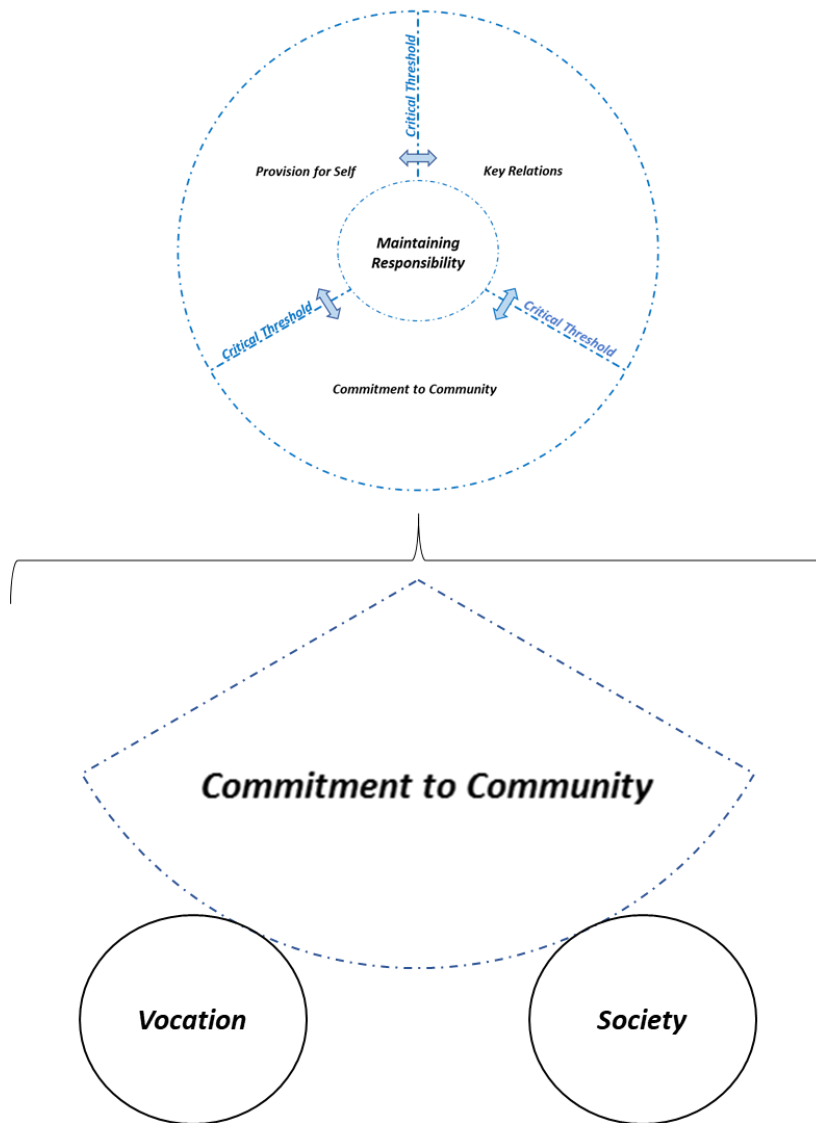


Figure 8: The Dimensions of *Commitment to Community: Vocation and Society*

5.3.3.1 Vocation

The first dimension of *commitment to community* is *vocation*, or the responsibilities which people with advanced cancer assume within their work or occupation. As an employee, the participant requires modifications to work duties and flexibility in work arrangements due to symptom fluctuations and functional decline. Those who are self-employed are accountable for transitioning the management and day-to-day business operations elsewhere in

anticipation of their eventual passing. *Vocation* can be a fundamental component of daily routine, the void of which cannot otherwise be filled.

ACT10: I mean that's part of why I got into what I do, so not having that is like double, double whammy almost, number one [I'm] not working...I think that is important because I don't know, I love what I do, I love helping the kids, you know...it's just [pause] it really sucks not being able to do any of that, you know?

5.3.3.2 Society

Society is the second dimension of *commitment to community*. This is viewed as responsibility for the welfare of others and accountability to the collective good. As a mentor, the person with advanced cancer draws from knowledge and experience to provide guidance. As a volunteer, making a positive contribution to the lives of others, no matter how small, is meaningful. The desire to help others can supersede personal interests, even in the face of disease progression and symptom fluctuation.

ACT15: And I do a lot of volunteer things too, they're also extremely important to me, so. Um, so that's another thing that people are telling me: "drop that stuff, drop that stuff" ... I'm president of the [local political association], so we're getting ready for election, and then I'm also the chair of the [learning and literacy association], and I have other things too that I have, that are on the back burner, but those two things I keep up with...so then I'm always thinking, well should drop them, or you know, should resign from them, but...[pause] so far I haven't. It's a big thing for me too, community, building community, contributing, yeah, that's a big thing for me, yeah.

5.4 The Decision-Making Strategy: *Downsizing*

The *critical threshold* is the minimum level of responsibility to be met, and the degree to which the *critical threshold* encompasses the three sub-categories of *provision for self*, *key relations* and *commitment to community* can fluctuate over the course of the disease.

Downsizing is viewed as scaling back to the *critical threshold*, given the prevailing conditions at that point in time. *Downsizing* involves making decisions, both consciously and subconsciously, that prioritize the most essential responsibilities. *Downsizing* involves participants asking the following questions of themselves: 1) what am I still able to do with the time that remains, 2) what are the most important responsibilities to address given limited prognosis, and 3) at this point in time, what should I be doing that reflects these priorities. Decisions regarding responsibilities are not final, but can change over the course of disease.

ACT15: I'm not sure what's happening with work, I might just say I'm done...it's becoming less important right? I'd really rather just be doing temple and qi gong and you know, so that's kind of what I'm hoping, that I might just move more into that, forget working, we'll see.

Downsizing results in the *critical threshold* being in a state of flux at any given moment (see Figure 9). As symptom burden and functional limitations increase, *downsizing* can entail meeting the responsibility of *provision for self*, to the exclusion of *key relations* or *commitment to community*. *Downsizing* continually revises the degree to which the *critical threshold* encompasses its three sub-categories.

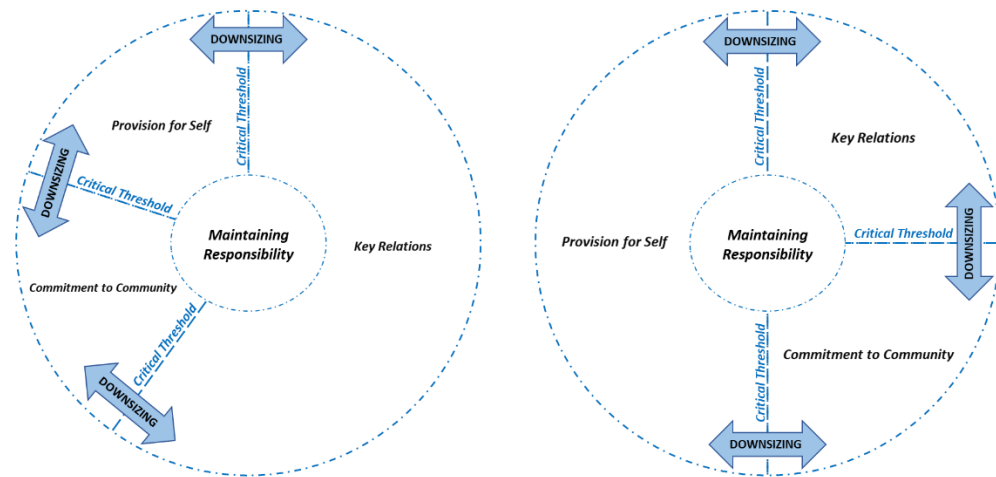


Figure 9: Downsizing to the Critical Threshold: A State of Flux

For the person with advanced cancer, the *critical threshold* is in a constant state of flux over the course of the disease. The benefits and conditions which influence this state of flux, and the mechanisms used to meet the *critical threshold*, will be explored in Chapter 6.

5.5 Summary

Chapter 5 described the central tenets upon which the emergent theoretical framework is based, using a classic grounded theory approach. *Maintaining responsibility* emerged as the main concern of participants in this study, with the *critical threshold* being the core conceptual category which accounts for how this main concern is managed. The extent to which the *critical threshold* involves each of its sub-categories (*provision for self*, *key relations* and *commitment to community*) is unique to each person with advanced cancer. With respect to *provision for self*, the person with advanced cancer can address each of its three dimensions (*self-care*, *self-management of health* and *self-sufficiency*) in order to meet the *critical threshold*. With respect to *key relations*, the person with advanced cancer can address one or more of its five dimensions (*role as caregiver*, *role as spouse*, *role as parent*, *role as adult child*, and *role as grandparent*) in order to meet the *critical threshold*. With respect to *commitment to community*, the person with advanced cancer can address either

of its dimensions (*vocation* and *society*) in order to meet the *critical threshold*. *Downsizing* is the decision-making strategy used by participants to scale back to the *critical threshold*.

Having described the foundation of the emergent theoretical framework in Chapter 5, Chapter 6 will expand upon these central concepts by presenting the typology of benefits and conditions which influence *downsizing*, and the mechanisms which enable the *critical threshold* to be met.

Chapter 6: The Emergent Theoretical Framework: Benefits, Conditions and Mechanisms

6.1 Introduction

Chapter 5 described the principal tenets upon which the emergent theoretical framework is based: the participants' main concern of *maintaining responsibility*, the core conceptual category of the *critical threshold*, and the participants' decision-making strategy of *downsizing*. Chapter 6 builds upon this foundation by exploring the categories which influence *downsizing* and that enable participants to meet their *critical threshold*. The emergent theoretical framework will be further developed using data from the literature review presented in Chapter 7, and the final grounded theory will be discussed in Chapter 8.

Chapter 6 begins by detailing the typology of benefits, which are the positive effects of *maintaining responsibility*, and the typology of conditions, which are the determinants that influence *downsizing* to the *critical threshold*. The dynamic interplay between benefits and conditions which lead to *downsizing* is discussed. This is followed by description of a typology of mechanisms, or the means which enable people with advanced cancer to meet their *critical threshold*. Each concept of the emergent theoretical framework is addressed in separate sections of this chapter. Direct participant quotations are used to illustrate each concept. As before, all study participants, each of whom are identified by the letters "ACT" and a number (1-15), are represented in this and the previous chapter.

6.2 The Benefits of *Maintaining Responsibility*

Benefits are viewed as positive effects which result from managing the main concern of *maintaining responsibility*. Their occurrence and manifestation are unique to the individual experience. These benefits can change and be perceived differently over the course of disease. People with advanced cancer evaluate these benefits within their individual context

in order to determine the *critical threshold*. When participants are unable to resolve their main concern, the loss of these benefits can be acutely felt.

ACT03: Well I have to be able to do something, I'm not contributing anything to this world right now, and not to me really. I still have to be useful for something...Not just be here, and fill up space sort of thing. I have to, I have to still be able to feel like I'm contributing.

Five sub-categories of the benefits of *maintaining responsibility* emerged from this study of activity in people with advanced cancer: purpose, contribution, identity, accomplishment and locus of control (Figure 10). People with advanced cancer can glean one or more of these benefits when they meet their *critical threshold*. In the following sub-sections, purpose is discussed first, then contribution, followed by identity, accomplishment, and finally locus of control.

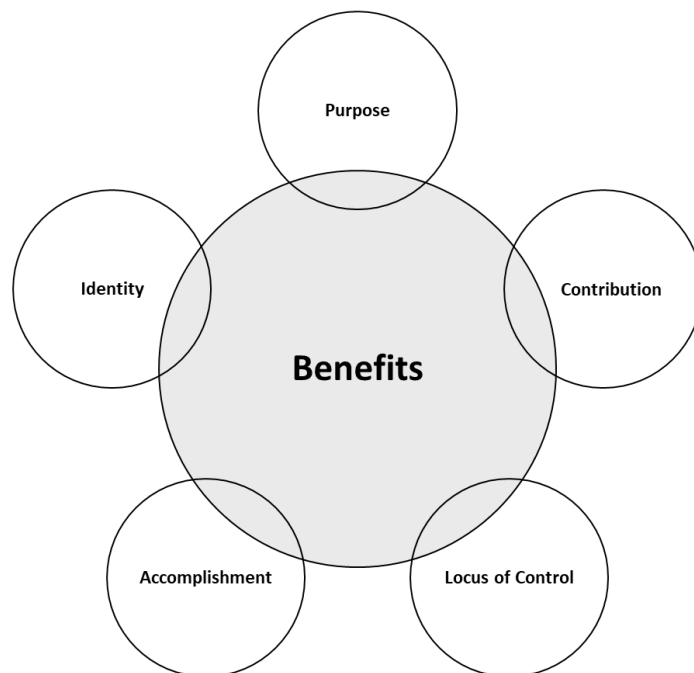


Figure 10: The Benefits of *Maintaining Responsibility*

6.2.1 Purpose

The first benefit of *maintaining responsibility* is purpose. Purpose is viewed as the reason for which a certain task or duty is carried out. Purpose can be derived from fulfilling the responsibility of *key relations*, when the participant is the sole caregiver for a dependent. Taking on different responsibilities can foster a sense of purpose.

ACT09: To me, too, laundry's personal...and that's the way my mother taught me, you know. So I'm particular, so that, and it does give me, it also does give me a sense of purpose, that I'm doing something for myself and I'm not relying on my daughter or my son.

6.2.2 Contribution

The second benefit of *maintaining responsibility* is contribution, which is viewed as the part played by an individual in carrying out a task or duty. The person with advanced cancer can seek to feel useful to others, no matter how small the contribution. People with advanced cancer can take pride in what they are able to contribute.

ACT13: I want to be doing stuff, I don't want to be laying around in this couch and sitting around and doing nothing. I want to be busy, I want to do stuff, I want to be a part of life... Well even to our family, right? Just contribute. Be a part of everything again, you know?

6.2.3 Identity

The third benefit of *maintaining responsibility* is identity, which is viewed as the characteristics which define the participant's self-concept or individuality. Addressing *key relations* can reinforce the participant's sense of self as belonging within the family and household. Addressing responsibilities can reflect the desire to live as close to one's personal norm as possible, and to lead a day-to-day life typical to that of peers or loved ones. Meeting

the *critical threshold* can re-affirm personal values and beliefs, guide day-to-day living, and help in regaining a sense of normality and self.

ACT11: you're not just sitting there and watch life pass you by, you know, I'm sick, but I'm not an invalid, you know? So...I just, I'm going to participate until the end. So to me this is just...I'm living.

6.2.4 Accomplishment

The fourth benefit of *maintaining responsibility* is accomplishment, which is viewed as the achievement of goals or fulfilment of a task to completion. People with advanced cancer can take pride in meeting the *critical threshold*, to whatever degree that they are able. Dignity is not measured by ability, but rather by what the participant is able to accomplish with what they have. By meeting the *critical threshold*, this sense of accomplishment can be perceived as even greater at the end of life.

ACT06: even though it's not a lot, when you are still able to get from A to B, and sometimes you need assistance, but still, you're able to do something, you feel like you've accomplished something, and I think that makes you feel better.

6.2.5 Locus of Control

The fifth benefit of *maintaining responsibility* is a locus of control. During the course of disease, people with advanced cancer can feel as if they do not have a sense of control over their circumstances. Meeting the *critical threshold* can preserve a locus of control in the face of inevitable death. There can be a desire to complete those tasks which the participant is still able to do independently.

ACT09: sometimes my daughter will insist on doing this, and I'll say "[her daughter's name]! Let me do something that I can do!" She'll apologize and she'll say, "ok Mom"

6.3 The Conditions of *Maintaining Responsibility*

At any given point in time, the person with advanced cancer can experience a combination of the previously described benefits, and prevailing conditions. Conditions are the contingency factors which impact *downsizing* to the *critical threshold*. The presence, intensity and frequency of these conditions are unique to the individual experience. Towards the end of life, conditions can change from day to day, and in ways that cannot be anticipated. Factors which support the initiation of a task, may not be sustainable for its completion. Depending upon the prevailing conditions, duties can be perceived as easier or more challenging to address. Evaluating these conditions within the participant's individual context is crucial in *downsizing* to the *critical threshold*.

ACT08: I'm fine with what it was, you know, you just, you don't know what to expect, you know, it affects people differently too, right? So, I mean I would have liked to have done more, you know but, expectation wasn't there after being through five previous treatments, you know so I mean it was, it was a progression, it got progressively worse, so um yeah, by the end the expectation was that I'm not doing anything this week, so.

Nine conditions of *maintaining responsibility* emerged from this study of activity in people with advanced cancer: understanding of illness, symptom burden, physical functioning, disease and symptom treatment, day-to-day fluctuations, acute stressors, environment layout, person supports and equipment supports (see Figure 11). These conditions will be explored in the following subsections: understanding of illness is discussed first, then symptom burden, followed by physical functioning, disease and symptom treatment, day-to-day fluctuations, acute stressors, environment layout, person supports, and finally equipment supports.

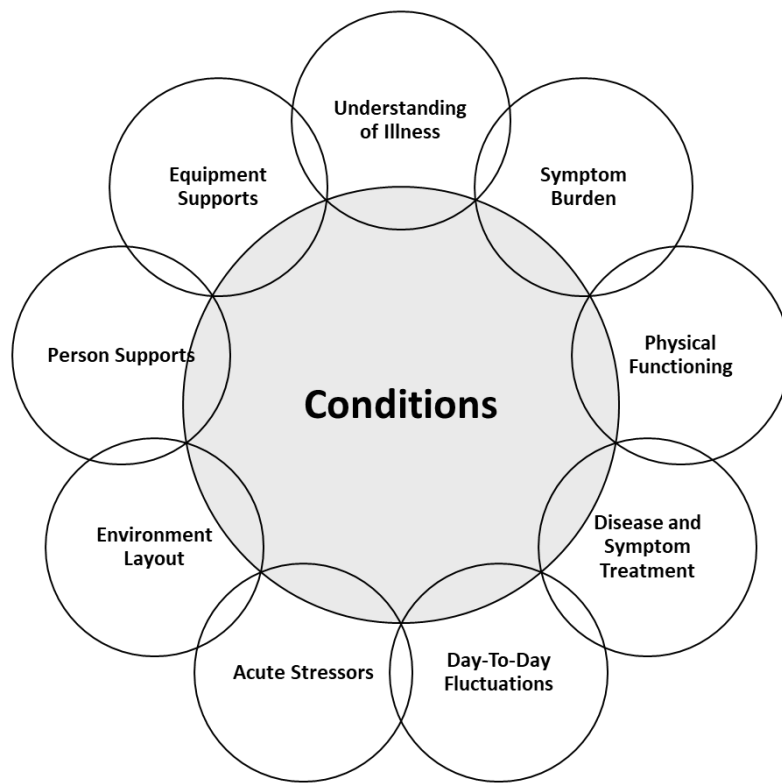


Figure 11: The Conditions of *Maintaining Responsibility*

6.3.1 *Understanding of Illness*

The first condition of *maintaining responsibility* is the understanding of illness, which is the knowledge of the progressive, incurable nature of the disease and its prognostic implications. This knowledge informs the participant's expectations with regards to the course of illness, the associated symptom burden, and the anticipated level of functioning. The understanding of illness prompts pragmatic consideration of the future supports that will be required, in advance of functional decline. Knowledge of the progressive disease burden influences the prioritization of responsibilities, and subsequent *downsizing* to the *critical threshold*.

ACT06: I don't anticipate doing anything that's, that's mind-altering at this point, or physically going to do anything great, so yeah, it's um kind of coming to the end of the road, and recognizing that that's where I am

6.3.2 Symptom Burden

The second condition of *maintaining responsibility* is symptom burden, which is perceived by people with advanced cancer as a constant reminder of the progressive, incurable nature of the disease. With high symptom burden, relatively simple tasks can take a prolonged period of time to complete. Multiple symptoms can have synergistic effects, such that the person with advanced cancer has neither the motivation nor energy levels needed to meet the *critical threshold*. Symptoms exact an intense physical and emotional toll, which challenges the participant's ability to address *provision for self*.

ACT09: they're very tender and tight, it's just you know I bend them and you can just feel how tight they are, how tight they are and full of fluid, but it's when I have to lift, like even going out to our patio or to our deck, it's a tiny little bit of a step, and it's just like oh! Lifting heavy weights

Pain and fatigue emerged as distinct dimensions of symptom burden in this study of activity in people with advanced cancer, both of which are considered below.

6.3.2.1 Pain

Pain is a dimension of symptom burden, and amongst the most debilitating symptoms experienced by people with advanced cancer. Pain can be perceived as a physical barrier to meeting the *critical threshold*. Pain that increases with movement can severely restrict mobility and challenge the participant's *self-sufficiency*. Likened to an adversary, pain can be perceived as a physical threat to the responsibility of *provision for self*.

ACT13: Well, I'd get up in the morning, get dressed, go to work, work all day, you know do all the stuff I need to do in a day, come back home and do stuff at night, you know, like I'd...just like any other active person, you know? And then now that...[pause] all this pain has come along with it, it's just, it's kicking the crap out of me.

6.3.2.2 Fatigue

Fatigue, the other distinct dimension of symptom burden, is viewed as the subjective feeling of tiredness and lack of energy. Just maintaining *self-care* can be exhausting for the person with advanced cancer, and towards the end of life, additional supports could be required in order to manage even simple tasks. People with advanced cancer perceive fatigue as a physical barrier to meeting the *critical threshold*.

ACT05: You know, uh, some days I really can't be active, eh, because I just feel really tired and worn out stuff like that...yeah, like I was just totally worn out eh, just slept all day.

6.3.3 Physical Functioning

The third condition of *maintaining responsibility* is physical functioning, which is the perception of the actual ability to perform tasks. The decline in physical functioning can necessitate prioritization of essential responsibilities. The person with advanced cancer can perceive generalized weakness as the experience of no longer being able to rely on one's own body. Difficulty in negotiating position transfers, such as getting into and out of a bathtub, can impede the participant's ability to address *self-care*. Declining mobility, such as difficulty climbing stairs or walking on flat ground, can challenge the ability to address *self-sufficiency*. Additional supports and task modifications could be required for the person with advanced cancer to meet the *critical threshold*.

ACT10: you know like the other day I was trying to tie a bag onto my balcony to put bottles in, I couldn't even tie the bag because I can't bend, you know. To put, change the garbage bag in my garbage, well you have to bend to do that. To take your dishes out of your dishwasher, you know, you don't think about that stuff until you can't do it.

6.3.4 Disease and Symptom Treatment Strategies

The fourth condition of *maintaining responsibility* is disease and symptom treatment strategies. Palliative chemotherapy, palliative radiotherapy and palliative procedures aim to alleviate symptom burden and thus enable the person with advanced cancer to manage the main concern of *maintaining responsibility*. The person with advanced cancer could plan tasks according to the timing of administration of treatment, and to predict when the nadir, wherein the presence and intensity of sequelae is lowest, will occur.

ACT01: I'm on the hormone treatment, its slowing the testosterone down. There's nothing I can do about it other than deal with it...You have to accept it the way it is. [pause] Not like I'm gonna run 100 yards dash down the track so I don't even think about it. [pause]

6.3.5 Day-to-Day Fluctuations

The fifth condition of *maintaining responsibility* is day-to-day fluctuations. Symptom burden and physical functioning can change rapidly from one day to the next. Symptom onset, frequency and intensity can show high variability and volatility, with no identifiable precipitant. Physical functioning can likewise decline rapidly, with no warning, over the course of one day. This unpredictability renders previously planned tasks undeliverable. Day-to-day fluctuations can severely disrupt the ability of people with advanced cancer to meet the *critical threshold*.

ACT03: it's most annoying because I feel really good and then all of a sudden, I think I'm going to do something and all of a sudden the dizziness is back again, so yeah.

6.3.6 Acute Stressors

The sixth condition of *maintaining responsibility* is acute stressors. These are events which are unexpected setbacks, such as hospitalization, or where bad news is delivered. Acute stressors require the person with advanced cancer to re-evaluate *downsizing* to the *critical*

threshold. The reaction to acute stressors can take the form of grieving and seeking support from others, or could involve withdrawal from their responsibilities.

ACT10: It was good knowing like the results, there was that little bit of relief just in knowing, but it wasn't good news, so, yeah, I was really upset obviously, frustrated, um...[pause]...yeah I don't know I didn't feel like doing much basically. Kind of just yeah, I get really like down and then I just don't do anything, I won't make food or eat or anything

6.3.7 Environment Layout

The seventh condition of *maintaining responsibility* is environment layout. This refers to the physical setting in which the majority of day-to-day activities takes place. Physical obstacles in the environment layout can challenge the participant's ability to meet the *critical threshold*. Relocation to a smaller space could be optimal to meet *self-sufficiency*. Declining mobility could necessitate a setting wherein the required amenities are located on the same level. Feeling safe and having access to support within the environmental layout is valued.

ACT15: the only reason we moved was because of my health issues, it wasn't a good house for me...it was three levels and it's on a hill which is so treacherous. I wouldn't have been able to get out of the house at all, off the hill.

6.3.8 Person Supports

The eighth condition of *maintaining responsibility* is person supports: family members, friends or health care team members who provide physical assistance and psychosocial support to the person with advanced cancer. Irrespective of the intentions of health care team members, the person with advanced cancer could perceive them as not sharing the same goals. People with advanced cancer can have difficulty acknowledging the need for person supports. Appreciation for personal supports does not diminish the participant's desire to continue to feel useful to others. Although extensive person supports could be

required, the person with advanced cancer still finds meaning and personal satisfaction in meeting the *critical threshold*. Having access to live-in person supports is beneficial in meeting *self-sufficiency*. Planning for person supports could enable the completion of specific tasks which otherwise would not be feasible.

ACT10: Because I have somebody there, right? Like we'll go grocery shopping and stuff and you know he'll come with me, as long as I'm leaning on a cart or something, I'm ok. But still, like he's gotta come with me and helps me out, right? If something's low, he can grab it, stuff like that.

6.3.9 Equipment Supports

The ninth condition of *maintaining responsibility* is equipment supports, the physical items which assist the person with advanced cancer in meeting the *critical threshold*, particularly outside the home environment. The person with advanced cancer can have difficulty acknowledging the need for equipment supports. Stationary equipment supports, such as raised toilet seats and tub grab bars, could be necessary to meet *self-care*. Mobility aids, such as walkers or wheelchairs, could be required to meet *self-sufficiency*. Equipment supports can reduce the risk of harm or bodily injury such that the *critical threshold* can be met.

ACT14: if there's a wheelchair at the shop, if there's a cart at the shop, if there's some shopping cart that I can push and steady myself on. But mostly, yeah, the walker's mainly for the home.

6.4 The Mechanisms of *Maintaining Responsibility*

Mechanisms are the working means by which the person with advanced cancer carries out their tasks and obligations. The combination of and degree to which mechanisms are utilized are unique to the individual experience. The participant's choice of mechanisms is

dependent upon the perceived benefits and presence, intensity and frequency of prevailing conditions.

ACT03: I do that quite often, though, I just mentally think of ok, what I have to do, ok and what I can do, that's a little different thing, and then [her friend] is coming to stay with me for the last couple of weeks...and there's a few things I want to do which I don't want to start myself, because I couldn't finish it. So therefore I wait until she comes down.

At any given point in time, the person with advanced cancer can utilize different mechanisms in order to meet the *critical threshold*. Seven diverse mechanisms of *maintaining responsibility* emerged from this study of activity in people with advanced cancer: delegating, transferring, goal setting, day-to-day routine, path of least resistance, pacing and activity (see Figure 12). In the following sub-sections, delegating is discussed first, then transferring, followed by goal setting, day-to-day routine, path of least resistance, pacing, and finally activity.

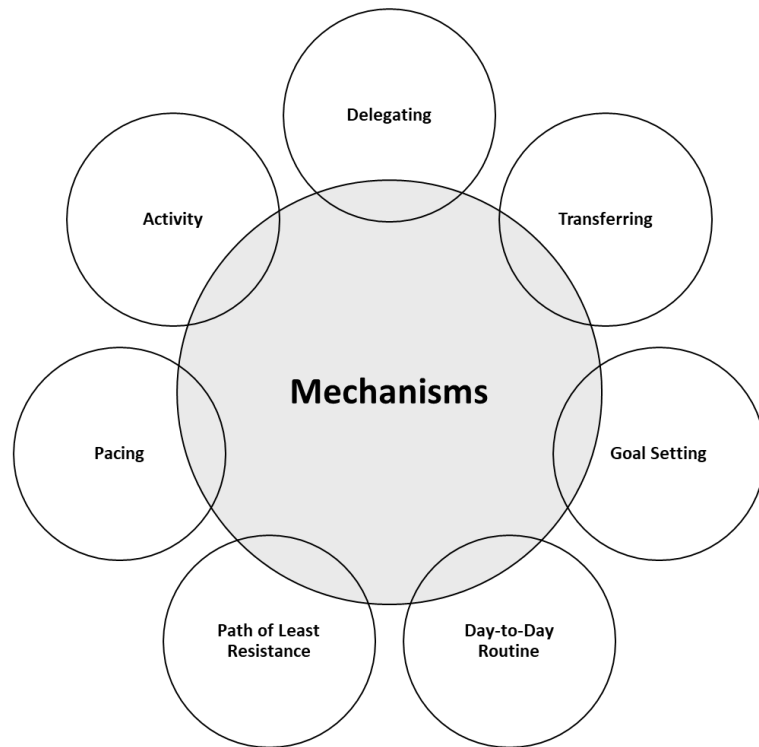


Figure 12: The Mechanisms of *Maintaining Responsibility*

6.4.1 *Delegating*

Delegating, the first mechanism of *maintaining responsibility*, is viewed as a temporary assignment of obligations to others, with the expectation that the person with advanced cancer will be able to resume after a defined period of time. This could entail finding the individual who would be best suited for the specific duty, and providing training and education about it. Compromise could be required between the participant's personal preferences and other individuals' methods of completing certain tasks.

ACT04: I used to do all the grocery shopping and driving here there and everywhere, going to the library, getting books, well, now the gal that cooks, gets the groceries, because I just can't walk around that much.

6.4.2. *Transferring*

The second mechanism of *maintaining responsibility* is transferring, which is viewed as a permanent assignment of obligations to others, with little or no expectation that the person

with advanced cancer will be able to resume. The understanding of illness can prompt the person with advanced cancer to plan in advance for this mechanism. High symptom burden and acute stressors could necessitate delegating on an urgent basis. This mechanism is predicated upon the person with advanced cancer acknowledging that a specific duty cannot be met alone, and accepting assistance from others in order to do so.

ACT15: my daughter, obviously, so I have to make sure, but you know she's really very independent, she's taken on so much, I don't, she knows that I can't do, I can't drive her places as much, and you know she knows that she has to take on extra responsibilities herself too, like I can't shovel, I can't take the dogs out, there's lots of things I can't do. So she knows she has to do them. And she knows that I would be doing them if I could, yeah...but she takes care of them.

6.4.3 Goal Setting

Goal setting, the third mechanism of *maintaining responsibility*, refers to the organization and advance planning needed to meet the *critical threshold*. The understanding of illness and awareness of limitations can provide the impetus for defining goals and formulating a plan to address them. The goals are set according to the participant's *critical threshold*, and their expectations about how it will be met. High symptom burden and decline in physical functioning could preclude meeting initial goals. Day-to-day fluctuations could necessitate the revision of goals and expectations. Tension can exist between what the person with advanced cancer would like to do, and what is feasible to do in reality.

ACT14: Oh, my first thing on my list is I'd love to get myself active enough that I can be walking around my home, and getting everything in shape for the next step of my life, which would be downsizing one business, and um and uh um just downsizing. I'd love to be...active enough to participate in that, the next 3 to 6 months, to get my ducks in a row.

6.4.4 Day-to-Day Routine

The fourth mechanism of *maintaining responsibility* is day-to-day routine. This refers to the participant's typical daily pattern of behaviour, whose structure reflects the *critical threshold* to be met. Environmental layout, and person and equipment supports affect the implementation of this mechanism. Flexibility in altering day-to-day routine could be required in response to symptom burden and treatment-related sequelae. Scheduling during optimal times of day, allocating additional time for specific tasks, and integrating rest periods can facilitate the participant's ability to meet the *critical threshold*.

ACT10: usually I find like I wake up, I go lay down for a bit on the couch, and then after that is kind of when I'm the most active like, that's when I have the most, I don't know I seem to be in the least amount of pain, as the day progresses, I get more and more kind of sick, so when I have the energy, I use it to my full advantage, so I'll do the laundry or if there's cleaning that needs to be done, I'll do it then, so. So that kind of time is usually the best for me.

6.4.5 Path of Least Resistance

The path of least resistance is the fifth mechanism of *maintaining responsibility*. This refers to the minimum energy expenditure required to meet the *critical threshold*. High symptom burden, treatment-related sequelae and decline in physical functioning could prompt the person with advanced cancer to revert to this mechanism. The path of least resistance can be appealing if the task has a high degree of perceived exertion. The person with advanced cancer could choose this mechanism with the intent of reducing stress and lowering the potential for injury or aggravating symptoms. At the end of life, the priority could be to do no more than what needs to be done to meet the *critical threshold*.

ACT10: I feel like maybe I could move around a little bit more, but sometimes it's hard you know you just don't want to, you know, and it goes so easy doing the same thing every day, you just fall into a routine of doing nothing almost

6.4.6 Pacing

Pacing, the sixth mechanism of *maintaining responsibility*, is the time taken before, during or after periods of exertion, in order to meet *self-care* and *respect for limitations*. Rather than expending energy all at once, pacing allows for energy levels to be sustained over the length of time needed to complete a task. This mechanism could be favoured with the intent of managing fatigue through energy conservation; additional time for rest and recovery, for example, could be planned the day before and after the anticipated period of exertion.

ACT12: maybe like some of the busy days were a little too much, yeah. It burns up my energy...I think if I do like have a busy afternoon, then after I need to rest for awhile, yeah.

6.4.7 Activity

The final mechanism of *maintaining responsibility* is activity. People with advanced cancer view activity as the day-to-day behaviours which enable them to meet their *critical threshold*. Everyday activities, such as bathing and showering, dressing, and functional mobility, enable the person with advanced cancer to meet *self-care* and *provision for self*. Other activities such as housework, shopping and transportation, enable the person with advanced cancer to meet *self-sufficiency* and *self-management of health*. Activity is prioritized more as a mechanism for meeting the *critical threshold*, rather than for its own sake.

ACT07: Being active, being able to do the things that I'd like to do, I'd like to be able to do that when I want to do it, but not doing it does not make me feel like I'm missing anything, yeah.

Treatment-related sequelae, high symptom burden, and decline in physical functioning can preclude activity as a mechanism to meet the *critical threshold*. If the person with advanced cancer experiences nerve-related pain, activity could be limited so as not to aggravate symptom burden. Increased fatigue can be a delayed sequelae of activity, and could be perceived as an additional physical burden. People with advanced cancer could perceive everyday activity as having a high degree of perceived exertion. Decline in physical functioning can impede position transfers, irrespective of equipment supports.

ACT10: Well to shower is hard...I have to just kind of lean on my thighs, but then, and just kind of like sit for a bit, leaning on my thighs. So I shower, like you know, it's usually fairly quick, it's trying to get it done. I shower quickly and then kind of like have to lean on my legs for a couple of seconds, minutes you know, and I get back up, shower you know. But it's a lot of leaning on my thighs, yeah.

Driving is an activity which enables the person with advanced cancer to meet the *critical threshold*. Driving confers access to people and resources outside of the home environment, which can modify conditions such that the *critical threshold* can be expanded. For example, the ability to drive enables contact with family and loved ones, thus meeting the sub-category of *key relations*; the ability to drive confers greater independence in attending health care appointments, thus meeting the dimension of *self-management of health*. Fluctuant symptom burden and medication-related sequelae could interfere with the ability to drive.

ACT10: And like I was complaining a couple months ago when I was already in the house, and now it's even worse, I feel like if I, I won't complain now, even if it, if I could just go back, you know, two months, I won't complain if I can you know, just the ability to drive, and like once that comes back, it opens up so many doors.

6.5 The Dynamic Interplay of the Benefits, Conditions and Mechanisms of *Maintaining Responsibility*

Downsizing is influenced by the dynamic interplay between the perceived benefits, prevailing conditions and mechanisms of *maintaining responsibility* (see Figure 13). The degree to which *downsizing* changes the *critical threshold* varies depending upon the push and pull of a combination of benefits and conditions; this subsequently influences the mechanisms used for carrying out these responsibilities. For example, supplemental oxygen can alleviate shortness of breath, thereby enabling the participant to meet the *critical threshold*. Potential treatment-related sequelae, such as increased fatigue and fatigue, can hinder the participant's ability to meet the *critical threshold*. Impaired concentration and cognitive sequelae can occur post-palliative chemotherapy, and are barriers to meeting the dimensions of *self-sufficiency* and accountabilities to *vocation*. Severe energy depletion can occur post-palliative abdominal paracentesis, and obstructs the participant's ability to meet the sub-category of *self-care*.

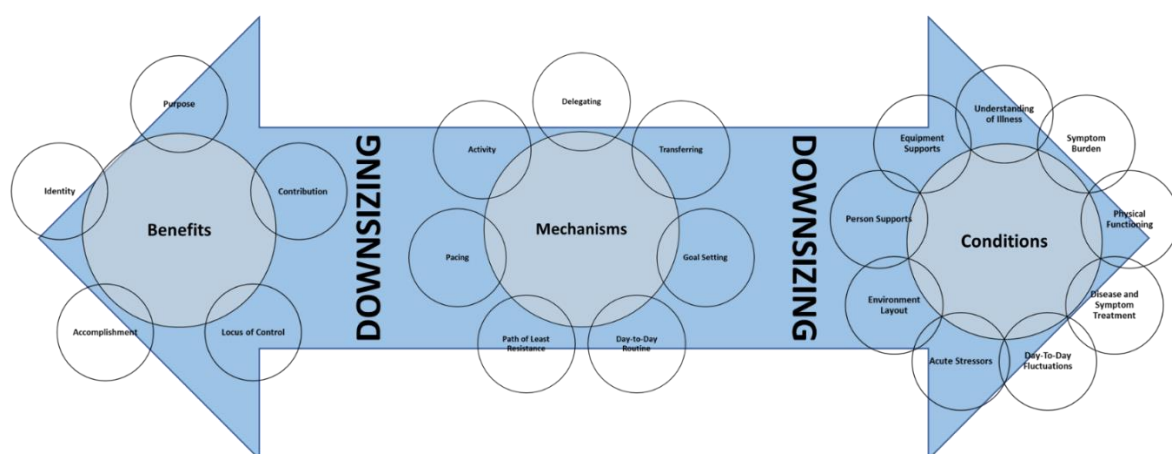


Figure 13: The Dynamic Interplay of Benefits, Conditions and Mechanisms

6.7 Summary

Chapter 6 elaborated upon the emergent theoretical framework by describing the benefits, conditions and mechanisms of *maintaining responsibility*. Benefits are the positive effects

which result from *maintaining responsibility*; five sub-categories of benefits emerged, including purpose, contribution, identity, accomplishment and locus of control. Conditions are the contingency factors which affect *downsizing* to the *critical threshold*; nine sub-categories of conditions emerged, including understanding of illness, symptom burden, physical functioning, disease and symptom treatment strategies, day-to-day fluctuations, acute stressors, environmental layout, person supports and equipment supports.

Mechanisms are the working means by which the person with advanced cancer is able to carry out their responsibilities; seven sub-categories of mechanisms emerged, including delegating, transferring, goal setting, day-to-day routine, path of least resistance, pacing and activity. There is a dynamic interplay between the perceived benefits and prevailing conditions of *maintaining responsibility*, which in turn influences the mechanisms which participants use to fulfil their responsibilities.

In keeping with a classic grounded theory approach, further development of the emergent theoretical framework will be pursued by a literature review examining responsibility in people with advanced cancer, which follows next in Chapter 7.

Chapter 7: A Literature Review of Responsibility in People with Advanced Cancer using a Classic Grounded Theory Approach

7.1 Introduction

Chapters 5 and 6 presented the emergent theoretical framework of *maintaining responsibility*. The aim of Chapter 7 is to describe the literature review on responsibility in people with advanced cancer, in order to provide further data for the development of the emergent theoretical framework. This is in keeping with a classic grounded theory approach. First, a justification of the timing and focus of the literature review is outlined. Next, the review methods including the review question, design, database and search strategy, inclusion/exclusion criteria, identification and selection of studies, data management and analysis, are discussed. The main findings from the literature review are then presented. This chapter concludes with a critical discussion on how the literature review further develops and refines *maintaining responsibility*.

7.2 Justification for the Timing and Focus of the Literature Review

As introduced in section 1.5.2 of Chapter 1, the timing of the literature review occurred after the core conceptual category and theoretical framework had emerged. This is congruent with the principles of classic grounded theory, wherein theory emerges from the conceptualization of empirical data, and not from extant theory (Glaser, 1978). When conducting a literature review *a priori*, there is a risk of preconceiving the grounded theory with concepts that did not emerge from the behaviour of participants under study. Given my previous systematic review of physical activity in people with advanced cancer (Lowe, Watanabe, & Courneya, 2009), this risk of preconception was minimized by the abeyance of the literature review. The literature review could not have been predicted in advance, as it was contingent on the core conceptual category that emerged from the empirical data of this study.

According to a classic grounded theory approach, extant literature is considered to be “just more data to be coded and integrated into the study through constant comparative analysis” (Holton, 2007, p. 50). In the literature review, I treated the extant literature as primary data that could offer new perspectives, modify or refine the emergent theoretical framework of *maintaining responsibility*. In keeping with a classic grounded theory approach, the concepts drawn from the extant literature were subjected to the same constant comparative analytic procedures, as described in Chapter 4. Thus the focus of the literature review was to explore the concept of responsibility in people with advanced cancer within the extant literature.

7.3 Aim of the Literature Review

The aim of the literature review was to build a comprehensive mid-level range theory of *maintaining responsibility* in people with advanced cancer.

7.4 Review Methods

7.4.1 Review Question

What is known about the concept of responsibility in people with advanced cancer?

7.4.2 Review Design

To date, there is no agreed upon method for literature reviews within a classic grounded theory approach (Holton & Walsh, 2017). I anticipated that: 1) the number of studies focussing exclusively on responsibility in people with advanced cancer to be small, and 2) the studies for inclusion to be diverse and include both quantitative and qualitative designs. Thus my priority was finding data that was relevant to the concept of responsibility in people with advanced cancer, as opposed to selecting study types that met specific methodological criteria. My unit of comparison was the concept drawn from, rather than the methodological origin of, the extant literature. I therefore adapted elements of critical interpretive synthesis

(CIS) methodology (Dixon-Woods et al., 2006) as the approach that would enable me to explore concepts in order to build upon the emergent theoretical framework of *maintaining responsibility*.

CIS combines the rigour of conventional systematic review methodology, in terms of search strategy and data extraction procedures, with methodological aspects drawn from qualitative enquiry (Dixon-Woods et al., 2006). Congruent with CIS methodology, I was exploring data at the level of concepts for the purpose of theory building, as opposed to data aggregation. The literature review diverged from CIS methodology, however, at the point of data analysis; concepts drawn from the extant literature were constantly compared to elaborate, saturate and develop the properties and dimensions of emergent concepts from this study, using the same step-by-step process of conceptual development as detailed in Chapter 4. This analytic process is consistent with the principles of classic grounded theory.

The literature review was thus designed to keep the literature search as wide as possible, while at the same time looking for the unique typology of responsibility within this wider literature. Any empirical research reporting on the concept of responsibility in people with advanced cancer was included. The key terms and definitions used in the review are listed in Table 3.

Table 3: Key Terms for the Literature Review

- | |
|--|
| <ul style="list-style-type: none">• Responsibility is the state of being accountable for, bearing a duty, or feeling an obligation towards something or someone.• Advanced cancer is progressive, incurable, and locally recurrent or metastatic cancer, with a clinician-estimated life expectancy of less than 12 months (Lowe et al., 2015). |
|--|

7.4.3 Information Sources and Search Strategy

A keyword search of MEDLINE (PubMed), Web of Science, PsycINFO, Academic Search Complete and CINAHL was performed in March-April 2016. Reference lists of all included

articles were hand-searched for additional studies. Studies were restricted to the English language. The MEDLINE (PubMed) search strategy, as shown in Table 4, was developed in collaboration with a subject librarian.

Table 4: Sample Search Strategy for MEDLINE (PubMed)

#1 "Neoplasms"[Mesh]
#2 cancer
#3 "Palliative Care"[Mesh] OR "Palliative Medicine"[Mesh]) OR "Terminal Care"[Mesh:NoExp]) OR "Hospice Care"[Mesh]
#4 "end of life" OR end-of-life OR end-stage OR "end stage" OR "terminal cancer" OR "advanced cancer" OR dying OR palliative OR hospice
#1 OR #2 = #5
#3 OR #4 = #6
#5 AND #6 = #7
#8 "Personal Autonomy"[Mesh]) OR "Paternalism"[Mesh]) OR "Self Concept"[Mesh]) OR "Choice Behavior"[Mesh]) OR "Decision Making"[Mesh]) OR "Patient Participation"[Mesh]) OR "Refusal to Participate"[Mesh]) OR "Sick Role"[Mesh]
#9 responsibility OR duty OR accountability OR obligation
#8 OR #9 = #10
#10 AND #7 = #11
#12 questionnaire* OR survey* OR interview* OR "focus group*" OR "case stud*" OR observ* OR "grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog* OR Qualitative OR quantitative OR "mixed methods"
#12 AND #11 = #13
#14 "view*" OR "experience*" OR "opinion*" OR "attitude*" OR "perce*" OR "belie*" OR "feel*" OR "know*" OR "understand*"
#13 AND #14 = #15

The combination of relevant headings and key words were modified as required for subsequent databases (see Appendix K). As concepts related to responsibility were anticipated to be mentioned indirectly throughout the included studies, there were no date

limits. Search results were exported to, organized and de-duplicated within Endnote X7 (Thompson Reuters, USA).

7.4.4 Inclusion / Exclusion Criteria

Only studies involving adult participants aged 18 years and older, and clinician-estimated prognosis of less than or equal to 12 months, were included. Empirical studies using qualitative, quantitative, or mixed methods designs were included. For articles which examined a heterogeneous group of varying diagnoses (i.e. cancer and non-cancer diagnoses) or stages of disease (i.e. stage I-IV cancer), only those studies wherein data was presented separately for the advanced cancer subgroup of interest were included.

7.4.5 Identification and Selection of Studies

Initial screening of resulting titles and abstracts was performed to identify all potentially relevant studies. If the article potentially met inclusion criteria by title and abstract, or if there was inadequate information to make a decision, full text copies of the article were retrieved. Full text studies meeting the inclusion criteria were imported into Endnote X7 (Thompson Reuters, USA).

7.4.6 Data Extraction

For each included study, data was extracted using a standardized form (see Appendix L). The data extraction form enabled the systematic identification of the research question, research methods, participant characteristics and findings from each included study. The data extraction form was pilot-tested on three randomly selected articles from an initial database search conducted in January 2016.

Congruent with CIS methodology, the literature review prioritised “signal (likely relevance) over noise (the inverse of methodological quality)” (Dixon-Woods et al., 2006, p. 4). In keeping with Glaser’s dictum that “all is data” (Glaser, 1998, p. 8), concepts drawn from empirical literature were treated equally as data. Therefore all studies meeting the inclusion

criteria were given equal consideration when constantly compared and analysed in relation to concepts of the emergent theoretical framework. As such, a quality assessment tool was not used.

7.4.7 Data Analysis and Constant Comparative Technique

In keeping with a classic grounded theory approach, extracted data were analysed using the same tri-level process of conceptual development as detailed in Chapter 4. Memos interrogated the data extracted from the included studies using the following questions: 1) “to what concept does this incident refer?” 2) to what property does this concept indicate?”, and 3) “to what dimension does this concept indicate?” (Glaser, 1998). Guided by these questions, ongoing constant comparative analysis between concepts drawn from the included studies was undertaken. Hand-sorting of memos (as detailed in section 4.4 of Chapter 4) facilitated integration of these concepts into the emergent theoretical framework. Data management and organization was supported by ATLAS.ti™ qualitative data analysis software (ATLAS.ti™ Inc., Germany).

7.5 Results of the Review

7.5.1 Overview of Included Studies

The electronic and hand searches yielded 5,433 studies, and the initial screening of titles and abstracts resulted in 25 papers for full text review (see Figure 14). Of these, 10 articles met the inclusion criteria and were included in the review (see Table 5). Study publication dates ranged from 2002 to 2013, and study designs included 9 qualitative studies and 1 mixed-method study. 2 studies were from the United Kingdom, 2 from the Netherlands, 2 from Hong Kong, 2 from Australia, 1 from New Zealand, and 1 from Sweden.

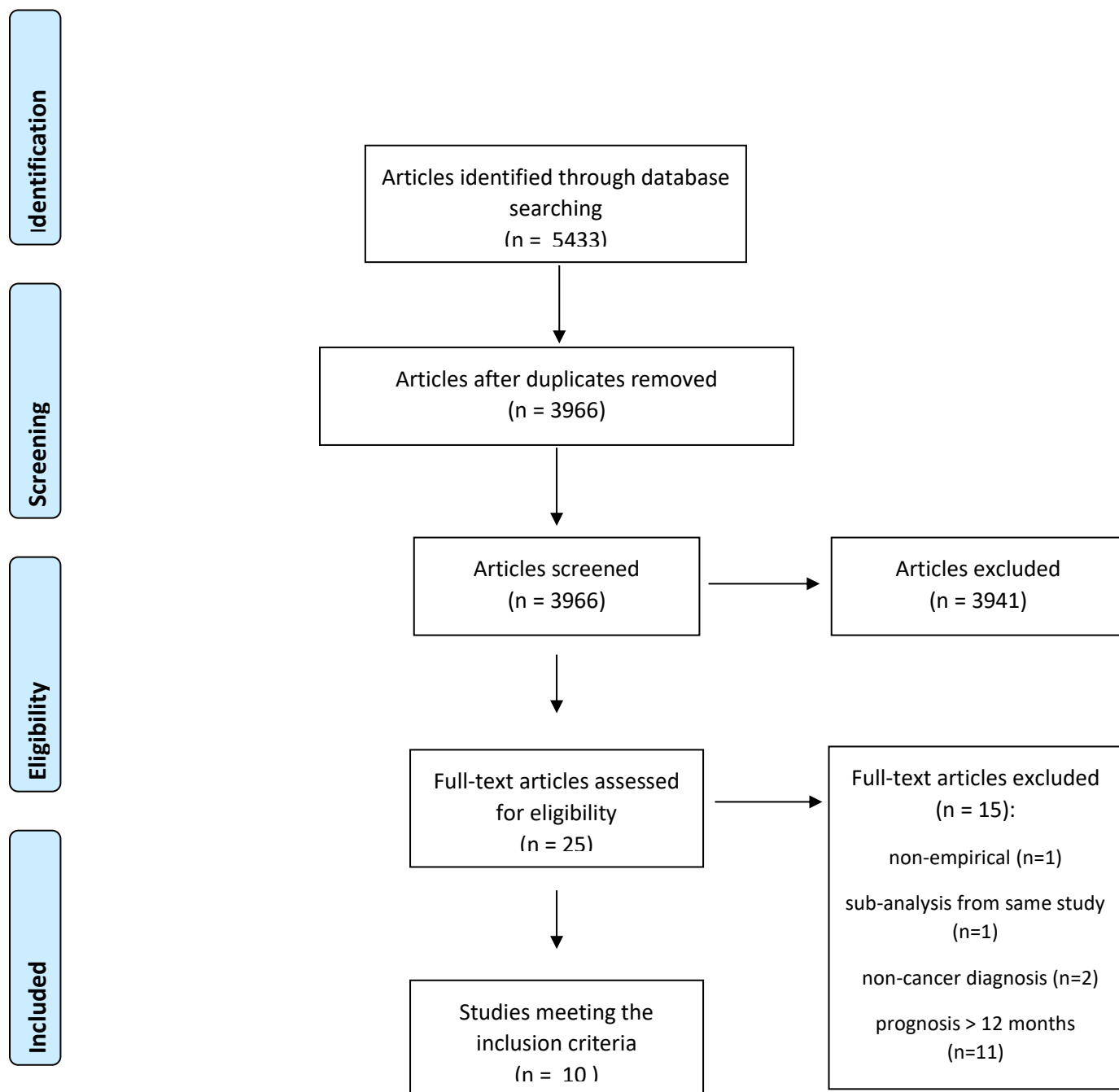


Figure 14. PRISMA flow diagram for study selection

Table 5. Data Extraction from Included Studies

Author (year), Country	Research Question	Participants	Method	Concepts related to Responsibility	Prevalence of Concepts related to Responsibility within Publication
Mak (2002) (Mak, 2002) Hong Kong	To explore what it means to die a 'good death' from the perspective of Chinese patients.	33 Chinese hospice inpatients with advanced cancer, 87% of whom died within 4 months of interview.	Semi-structured interviews. Analysis using grounded theory approach.	Familial obligation to complete social roles.	In the Abstract and Findings section: completion of social <i>obligations</i> identified as important towards acceptance of the timing of one's death. In the Discussion section: social <i>obligations</i> with respect to parental and children's roles discussed in light of Chinese cultural emphasis on filial piety.
Goldsteen et al. (2006) (Goldsteen et al., 2006) Netherlands	To explore how terminally ill patients use current normative ideas and expectations to define their dying trajectory.	13 advanced cancer patients at home, 70% of whom died within 3 months of interview.	Semi-structured interviews. Analysis using grounded theory approach.	Normative expectation to take care of one's responsibilities in practical everyday concerns and concern for loved ones after death.	In the Abstract and Findings section: taking care of one's final <i>responsibilities</i> identified as one category of normative expectation regarding what constitutes a good death.
Lethborg et al. (2006) (Lethborg, Aranda, Bloch, & Kissane, 2006) Australia	To examine the experience of meaning in advanced cancer patients within an integrated framework of assumptive world, sense of coherence and meaning based coping.	10 advanced cancer patients, with clinician-estimated prognosis between 6-12 months.	Semi-structured interviews. Thematic analysis.	Within the domain of living life fully, focus on roles and connectedness with loved ones.	In the Findings section: the domain of living life fully, with continued meaning, encompasses the concepts of roles and feeling connected to others.

Author (year), Country	Research Question	Participants	Method	Concepts related to Responsibility	Prevalence of Concepts related to Responsibility within Publication
Elliott and Olver (2007) (Elliott & Olver, 2007) Australia	To explore how hope is constructed and shaped discursively for terminal cancer patients.	28 advanced cancer patients, with clinician-estimated prognosis of less than 3 months.	Semi-structured interviews. Discourse analysis combining conversational and Foucauldian approaches.	Hope as a verb emphasized the patient's active engagement in life, used to assign responsibility to others.	In the Abstract and Findings section: because hope as a verb implies that the future is uncertain, <i>responsibility</i> can be disavowed irrespective of whether the preferred outcome materialises.
McKechnie et al. (2007) (McKechnie, MacLeod, & Keeling, 2007) New Zealand	To gather narratives of the lived experience of palliative care, and to explore images of embodiment function in social space.	7 female cancer patients receiving hospice care, 5 of whom died within several weeks of interview.	Semi-structured interviews using phenomenological approach. Thematic and interpretive analyses.	Handing over responsibility of physical care to health care professionals, thereby giving participants the energy to control other aspects of their lives. Nature of relationships change, roles need to be negotiated.	In the Abstract and Findings section: withdrawal from social <i>responsibilities</i> due to illness and treatment effects, negatively impacted participants. In the Discussion section: withdrawal from work <i>responsibilities</i> necessitated by illness and treatment effects.
Olsson et al. (2010) (Olsson et al., 2010) Sweden	To identify psychosocial processes used to maintain hope in a palliative home care setting by collecting and analyzing patients' subjective experiences.	11 cancer patients, 8 of whom died within 12 months of interview.	Semi-structured interviews and patient diaries. Analysis using grounded theory approach.	Maintaining hope was the patient's responsibility. Taking responsibility for loved ones even after death as part of maintaining hope.	In the Abstract and Findings section: taking <i>responsibility</i> for the future linked to preparing for death. In the Findings section: working on hope perceived as the individual's <i>responsibility</i> , feeling of <i>responsibility</i> through involvement with treatment decisions.

Author (year), Country	Research Question	Participants	Method	Concepts related to Responsibility	Prevalence of Concepts related to Responsibility within Publication
Reeve et al. (2010) (Reeve, Lloyd-Williams, Payne, & Dowrick, 2010) United Kingdom	To determine how the theoretical concept of biographical disruption, underpinned by an emphasis on narrative meaning, support understanding of illness experience and health need in individuals with terminal cancer.	19 cancer patients, with clinician-estimated prognosis of less than 6 months.	Semi-structured interviews within subtle realist approach. Holistic form and iterative content analyses.	A functional, rather than a reflexive account, of the individual self. Embodied experience underpinned individual capacity to maintain continuity of daily living.	In the Introduction section: maintaining a coherent sense of self outlined as a personal <i>responsibility</i> .
Johnston et al. (2012) (Johnston, Milligan, Foster, & Kearney, 2012) United Kingdom	To understand patient experiences of advanced cancer at end of life care, and what self-care strategies enable patients to cope with end of life care.	20 advanced cancer patients with clinician-estimated prognosis of less than 12 months.	Unstructured interviews. Framework approach to analysis.	Maintaining normality by drawing upon strategies for physical and emotional self-care, and family/friends for physical and emotional support.	In the Introduction section: study adopted extant definition of self-care as “maintaining ones usual practices of self-care—those things that are important and unique to oneself in maintaining ones sense of self...being given the means to master or deal with problems, rather than relinquish them to others” (p.1620) In the Findings section: themes focus on physical and emotional self-care strategies, support from family/friends and health care professionals.
Ho et al. (2013) (Ho et al., 2013) Hong Kong	To explore Chinese terminal cancer patients’ subjective experience and relevant interactive processes of maintaining dignity in the liminal space between living and dying.	18 Chinese advanced cancer patients receiving palliative care services with clinician-estimated prognosis of less than 6 months.	Narrative interviews. Qualitative content analysis.	To maintain dignity through personal autonomy, by ability to find small ways to maintain personhood and self-sufficiency. To maintain dignity through family connectedness, by fulfilling family	In the Abstract and Findings section: fulfilling family <i>obligations</i> identified as essential sub-process of family connectedness adopted by participants to maintain dignity.

				obligations and re-establishing roles.	
Author (year), Country	Research Question	Participants	Method	Concepts related to Responsibility	Prevalence of Concepts related to Responsibility within Publication
Ruijs et al. (2013) (Ruijs, Kerkhof, van der Wal, & Onwuteaka- Philipsen, 2013) Netherlands	To explore symptoms and unbearable suffering in end-of-life cancer patients in primary care.	60 advanced cancer patients, 46 of whom died within 6 months of interview.	Mixed methods with unstructured interview and SOS-V questionnaire. Thematic analysis of open questioning regarding unbearable suffering. Dichotomous and longitudinal analysis of SOS-V questionnaire.	Weakness was most frequent unbearable symptom. Not being able to do important things was unbearable irrespective of symptom intensity.	In the Abstract, Findings and Discussion sections: not being able to do important things, under domain of personal aspects, identified as unbearable irrespective of symptom intensity.

7.5.2 Findings on the concept of responsibility in people with advanced cancer

The literature review applied a low threshold to maximise the inclusion and data excavation of as many studies as possible for concepts related to responsibility in people with advanced cancer. Despite this, none of the included studies had an exploration of responsibility as their aim. Fingertip searching identified disparate studies with discrete pieces of data related to responsibility. A total of 63 conceptual memos were generated from constant comparative analysis of data extracted from the included studies. The following five concepts emerged from hand-sorting of memos generated from the literature review: 1) everyday matters; 2) uncertainty and disequilibrium; 3) autonomy; 4) staying connected; and 5) feeling supported.

7.5.2.1 Everyday Matters

The first concept, everyday matters, refers to the pragmatic issues which people with advanced cancer face on a day-to-day basis. The individual's effort is directed towards living daily life, with a functional emphasis on doing and being. Keeping up with day-to-day tasks and roles maintains normality and is a meaning-preserving endeavour for the person with advanced cancer (Olsson et al., 2010). The individual's life narrative is characterized by overall continuity of time spent on routine of normal everyday life (Reeve et al., 2010). Although responsibility was not the focus of these studies, elements of responsibility took shape in the practical concerns of day-to-day living for people with advanced cancer.

Addressing everyday matters can be related to normative, rather than personal, expectations, in that it reinforces the typical pattern of behaviour expected by society. Goldsteen et al. (2006) discuss taking care of one's final responsibilities as one of five categories of current western normative expectations surrounding what constitutes 'a good death'. For the person with advanced cancer, this normative expectation is based upon

practical everyday matters, as well as concern for loved ones after death (Goldsteen et al., 2006). Variability exists in the ways in which people with advanced cancer apply this expectation to their own individual context. These findings suggest that managing responsibilities can be influenced by the individual's perceptions of the norm.

7.5.2.2 Uncertainty and Disequilibrium

The second concept, uncertainty and disequilibrium, refers to the constant flux experienced by the person with advanced cancer. Uncertainty in the disease trajectory, combined with the variable impact of disease burden and treatment strategies, contribute to unpredictability in the daily reality of living with advanced cancer (Lethborg et al., 2006). Reeve et al. (2010) describe biographical fracture as a profound disturbance which overwhelms the individual's capacity to manage continuity of daily existence; examples of biographical fracture include severe emotional distress associated with learning of a terminal diagnosis, or urgent hospitalization secondary to an acute medical emergency (Reeve et al., 2010). Uncertainty and disequilibrium have the potential to severely disrupt everyday matters for the person with advanced cancer.

Within the domain of experiencing the reality of cancer, people with advanced cancer not only face uncertainty about the disease trajectory as a whole, but also wide variability in symptom burden in response to treatment strategies (Lethborg et al., 2006). In a study within community hospice palliative care, uncertainty permeates the day-to-day reality of living with the dying process (McKechnie et al., 2007). Uncertainty in symptom burden, on any given day, impedes the individual's ability to do what they want; being able to plan and carry out activities is limited. The normative expectation of "living one's life till the end", or staying active and involved even as death approaches (Goldsteen et al., 2006, p. 381), is often unfulfilled for people with advanced cancer. Not being able to do the things you consider important was identified by 63% (n=38), and deemed unbearable by 42% (n=25) of

participants (Ruijs et al., 2013). These findings suggest that managing tasks could be negatively impacted by uncertainty and disequilibrium.

7.5.2.3 Autonomy

The third concept is autonomy, which refers to the ability to address issues independently and the perception of the ability to do so. Even when symptom burden is overwhelming, the right to exercise choice is important for the person with advanced cancer to preserve dignity and maintain normality (Johnston et al., 2012). Ho et al. (2013) identify self-sufficiency as one of eight dignity-preserving processes for the Chinese person with terminal cancer (Ho et al., 2013). Lacking the physical ability to do tasks independently does not pre-empt the person with advanced cancer from being self-sufficient; self-sufficiency includes making decisions to access and draw upon support (Ho et al., 2013). Although the included studies in the literature review did not examine responsibility as the end goal, the behaviours associated with autonomy and are viewed as important aspects of the advanced cancer experience.

Loss of autonomy is associated with loss of physical functioning in terminal cancer; feeling dependent on others was reported by 80% (n=48), and deemed unbearable by 45% (n=27), of participants (Ruijs et al., 2013). The person with advanced cancer perceives the loss of ability to do basic and instrumental activities of daily living as a marker of disease progression and increased burden on family members (Johnston et al., 2012). Needing assistance from others for basic and instrumental activities of daily living is the personal aspect that contributes most to suffering in people with terminal cancer (Bragaru et al., 2013). As death approaches, relinquishing control to others could be necessary as the ability to address these issues becomes more limited (McKechnie et al., 2007). These findings indicate that changes in autonomy and loss of functioning negatively impact the individual's ability to manage tasks.

7.5.2.4 Staying Connected

The fourth concept is staying connected, which refers to maintaining bonds with family members and loved ones. There is increased awareness of the need to feel connected to loved ones, and renewed significance of roles which the person with advanced cancer plays within their household and family (Lethborg et al., 2006). The continuity of the individual's role within their family remains despite disease progression and symptom burden (Olsson et al., 2010). The way in which the person with advanced cancer carries out that role can change (McKechnie et al., 2007). Maintaining relationships was an important component of the advanced cancer experience in all of the included studies.

The person with advanced cancer engages in anticipatory care planning, including preparing loved ones, making funeral arrangements, and dealing with practical matters such as distributing belongings (Goldsteen et al., 2006; Olsson et al., 2010). Despite increasing dependence on loved ones, people with advanced cancer wish to alleviate perceived burden of physical care from loved ones, and to protect them from the distress and suffering of the dying process (McKechnie et al., 2007). Elliott et al. (2007) report that these activities give hope to people with advanced cancer for a positive future for their loved ones, and how hope in turn enacts and reinforces interpersonal ties between individuals (Elliott & Olver, 2007). These findings suggest that staying connected manifests itself in obligations towards loved ones.

For Chinese people with terminal cancer, family obligation is described as a life goal; a meaningful life is a responsible one, and Chinese hospice inpatients describe the completion of family and household roles as crucial at the end of life (Mak, 2002). Fulfilment of family obligation is a dignity-preserving process which involves mending unresolved family conflicts, re-establishing emotional connections within the family system, and establishing a continuing bond with future generations through transmission of life wisdom, traditions and

values (Ho et al., 2013). The Chinese person with terminal cancer makes informed care decisions to reduce perceived burden to loved ones, and to create a living legacy for themselves and for their families (Mak, 2002). These findings indicate a potential relationship between cultural background and perceptions of responsibility in the advanced cancer experience.

7.5.2.5 Feeling Supported

The fifth concept is feeling supported, which refers to the person with advanced cancer's perception of availability and access to assistance. Within the domain of responding to the impact of cancer, the person with advanced cancer recognizes the need for support, begins to see others as legitimate sources of support and care, and becomes open to receiving physical and emotional support from others (Lethborg et al., 2006). Towards the end of life, the negotiation of day-to-day tasks is dependent upon access to and availability of family members, friends or health care professionals (McKechnie et al., 2007). Drawing upon support from health care professionals, in particular, can relieve the sense of being a burden on loved ones (Ho et al., 2013). Reeve et al. (2010) report that during periods of biographical fracture, the person with advanced cancer relies upon external sources of help to restore continuity and well-being, and to increase their capacity to manage on a day-to-day basis. Across the studies in the literature review, feeling supported positively impacts the person with advanced cancer's ability to manage tasks and obligations.

7.6 Discussion

The purpose of the literature review was to provide data for further development of the emergent theoretical framework presented in Chapters 5 and 6, in order to build a comprehensive mid-level range theory of *maintaining responsibility* in people with advanced cancer. The theory identifies *maintaining responsibility* as the primary explanatory driver underlying the behaviour of people with advanced cancer; none of the included studies in

the literature review characterized this main concern. Concepts generated through constant comparative analysis of extracted data from the literature review, further substantiate elements of *maintaining responsibility*. Hand-sorting of memos resulted in greater illumination of the multidimensionality of *maintaining responsibility*, and articulation of the properties of its sub-categories, conditions, benefits, and mechanisms.

Incidents drawn from extracted data in the literature review are congruent with the benefits of *maintaining responsibility*. The sub-category of purpose is illustrated by the person with advanced cancer's feelings of worth as a positive outcome of being able to manage their own basic and instrumental activities of daily living (Johnston et al., 2012). The sub-category of contribution is reflected in the desire of people with advanced cancer to make a positive mark on the lives of others, despite symptom burden and disease progression (Lethborg et al., 2006; Olsson et al., 2010). The sub-category of identity is exhibited by the person with advanced cancer re-establishing a sense of self as one way to find healing despite suffering (Ho et al., 2013). The sub-category of accomplishment is demonstrated by the sense of personal achievement expressed by Chinese people with terminal cancer when fulfilling family obligations (Ho et al., 2013; Mak, 2002).

The concept of everyday matters, as generated from the literature review, is a property of the sub-category of *day-to-day routine*. As described in Chapter 6, *day-to-day routine* emerged as a mechanism which enables the person with advanced cancer to meet the *critical threshold*. Data extracted from the literature review highlight the importance of daily tasks and roles for people with advanced cancer; continuity in the practical issues of everyday life is valued. Thus everyday matters clarifies the scope of *day-to-day routine*, in that both its structure and continuity account for how people with advanced cancer manage their main concern (see Figure 15).

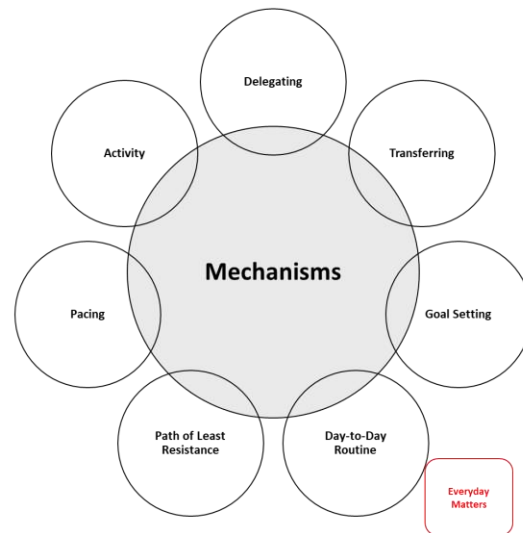


Figure 15: Everyday Matters: A Property of Day-to-Day Routine

The concept of uncertainty and disequilibrium, as generated from the literature review, is a property of the sub-categories of day-to-day fluctuations and acute stressors. As described in Chapter 6, day-to-day fluctuations and acute stressors are conditions which can modify the ability of people with advanced cancer to meet the *critical threshold*. Data extracted from the literature review depict varying degrees of the impact of uncertainty and disequilibrium on people with advanced cancer. On one hand, unpredictability in symptom burden can interfere with isolated day-to-day tasks; on the other hand, it can severely disrupt the participant’s life narrative (Reeve et al., 2010). Negotiating personal roles, performing social and occupational roles, and reinforcing connections to family members and loved ones are even more important in the face of unpredictability. Thus uncertainty and disequilibrium further articulates day-to-day fluctuations and acute stressors, in terms of the range of impact on how people with advanced cancer address their main concern (see Figure 16).

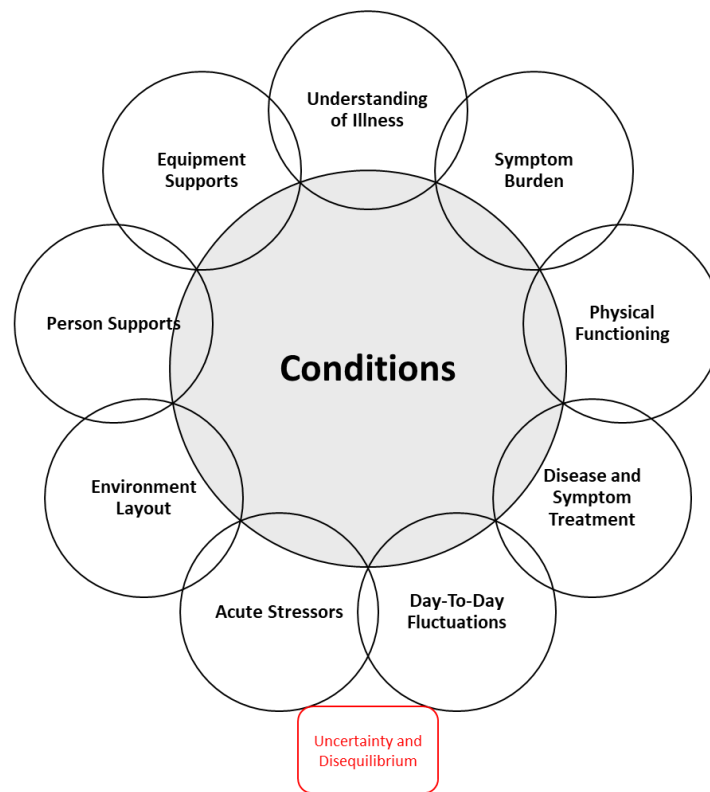


Figure 16: Uncertainty and Disequilibrium: A Property of Day-to-Day Fluctuations and Acute Stressors

The concept of autonomy generated from the literature review, is a property of the dimension of *self-sufficiency*. As described in Chapter 5, *self-sufficiency* is a dimension of the sub-category of *provision for self*. Data extracted from the literature review convey aspects of autonomy as acts of doing. People with advanced cancer value the act itself, in addition to the obligation it fulfils. Autonomy is viewed as distinct from functioning, as the loss of the ability to perform tasks independently does not preclude the person with advanced cancer being able to make choices which enable them to be self-sufficient. Thus autonomy expands upon *self-sufficiency* (see Figure 17).

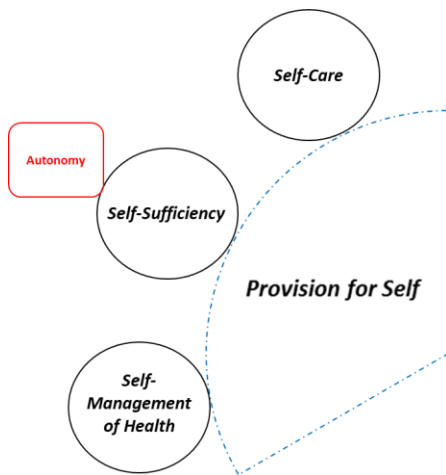


Figure 17: Autonomy: A Property of *Self-Sufficiency*

The concepts of staying connected and feeling supported, both generated from the literature review, are sub-categories of the benefits of *maintaining responsibility* (see Figure 18). Not only is staying connected perceived as a positive effect of meeting obligations within *key relations* and *commitment to community*, it is also enhanced by the mechanisms of delegating or transferring. Due to the effects of disease or treatment, the person with advanced cancer may need to relinquish some responsibilities to others, particularly with regards to physical care (McKechnie et al., 2007). This reinforces the connections between people with advanced cancer, their family and loved ones.

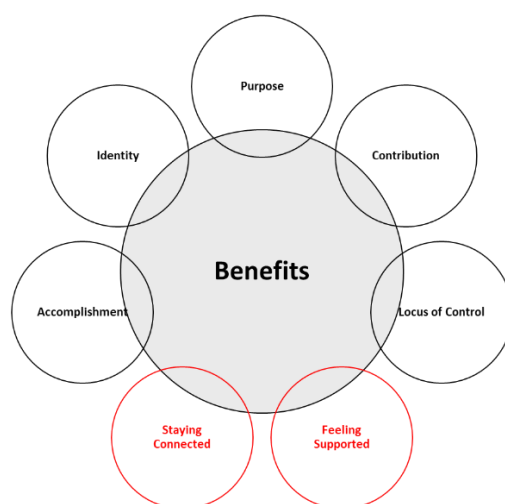


Figure 18: Staying Connected and Feeling Supported: Benefits of *Maintaining Responsibility*

7.7 Limitations of the Literature Review

The literature review search strategy terms were selected according to the concept of responsibility that emerged in this study of activity in people with advanced cancer. As the nomenclature of *maintaining responsibility* is unique to this study using a classic grounded theory approach, it may not encompass all of the language used by people with advanced cancer to describe this concept within the extant literature. As such, it is possible that relevant studies may have been missed in the literature review. Given the excavation required to extract discrete pieces of data in the included studies, it is also possible that studies that were excluded during screening of titles and abstracts, may have been relevant had they undergone full text review.

7.8 Strengths of the Literature Review

The literature review was rigorous in terms of its search strategy and data extraction procedures, and was inclusive of as many studies as possible for concepts related to responsibility in people with advanced cancer. Identification and selection of studies in the literature review were time-intensive, and fingertip searching and excavation was undertaken for discrete pieces of data within disparate studies. Data analysis in the literature review followed the step-by-step process of conceptual development articulated in Chapter 4, and congruent with a classic grounded theory approach.

7.9 Summary

Chapter 7 presented a literature review of responsibility in people with advanced cancer, using a classic grounded theory approach, in order to further develop and refine the emergent theoretical framework as presented in Chapters 5 and 6. The concepts of everyday matters, uncertainty and disequilibrium, autonomy, staying connected and feeling supported were generated from constant comparative analysis of data extracted from the literature review, and hand-sorting of memos facilitated integration with the emergent

theoretical framework. The findings of the literature review substantiate the benefits of *maintaining responsibility*, including purpose, contribution, identity and accomplishment. The findings of the literature review further articulate properties of the dimension of *self-sufficiency* (autonomy), and the sub-categories of day-to-day routine (everyday matters), day-to-day fluctuations and acute stressors (uncertainty and disequilibrium) in *maintaining responsibility*. The findings of the literature review add two additional sub-categories (staying connected and feeling supported) to the benefits of *maintaining responsibility*.

The final product of the literature review is *Maintaining Responsibility*, which will be summarised in Chapter 8, along with a critical discussion of its implications for the thesis' aim and objectives, evaluation of this grounded theory, and reflections on the research process.

Chapter 8: Discussion of activity in people with advanced cancer within the context of *Maintaining Responsibility*, evaluation of the grounded theory, and reflections on the research process

8.1 Introduction

This chapter presents *Maintaining Responsibility*, the final product of the emergent theoretical framework (presented in Chapters 5 and 6), and its subsequent development and further refinement from the literature review (presented in Chapter 7). This is followed by a critical discussion of the implications of this grounded theory for the aim and objectives of this thesis. In the first section, *Maintaining Responsibility* is summarized. In the second section, the experience of activity by people with advanced cancer is discussed in the context of the grounded theory. Next, the meaning, perceptions of and barriers and facilitators to physical activity by people with advanced cancer are considered. Lastly, *Maintaining Responsibility* is evaluated, and researcher reflexivity is considered.

8.2 Summary of *Maintaining Responsibility*

The end product of classic grounded theory is “a theoretical formulation or integrated set of conceptual hypotheses about a substantive area under study. That is all, the yield is just hypotheses!” (underlining by Glaser) (Glaser, 1992, p. 16). As detailed in Chapter 5, *maintaining responsibility*, or meeting the obligations which are incumbent upon the participant to fulfil, was the main concern of participants in this study. The *critical threshold*, or the minimum level of responsibility to be met, is the core conceptual category. The *critical threshold* encompasses *provision for self*, with its dimensions of *self-care*, *self-management of health* and *self-sufficiency* (including the property of autonomy); *key relations*, with its dimensions of *role as caregiver*, *spouse*, *parent*, *grandparent* and *adult child*; and *commitment to community*, with its dimensions of *vocation* and *society*. *Maintaining*

responsibility is addressed through *downsizing*, which is the participant's decision-making strategy to scale back to the *critical threshold*.

As detailed in Chapter 6, *downsizing* is determined by the dynamic interplay between the combination of perceived benefits and prevailing conditions; this subsequently influences the choice of mechanisms used for carrying out those responsibilities. The *critical threshold* is therefore a dynamic state, depending upon the perceived benefits (purpose, contribution, accomplishment, identity, locus of control, staying connected and feeling supported) and prevailing conditions (understanding of illness, symptom burden, physical functioning, disease and symptom treatment strategies, day-to-day fluctuations, acute stressors (including the property of uncertainty and disequilibrium), environmental layout, equipment supports and person supports) at any given moment. The combination of benefits and conditions also influences the choice of mechanisms (delegating, transferring, goal-setting, day-to-day routine (including the property of everyday matters), the path of least resistance, pacing, and activity) which enable people with advanced cancer to meet their *critical threshold*.

Maintaining responsibility, no matter how small, is the prime motive which explains the behaviour of people with advanced cancer in this study (see Figure 19). The *critical threshold* of responsibility is a dynamic state that is unique to each person with advanced cancer.

Downsizing to the *critical threshold* involves a multifaceted interaction between the perceived positive effects, the prevailing conditions and mechanisms of *maintaining responsibility* for the person with advanced cancer.

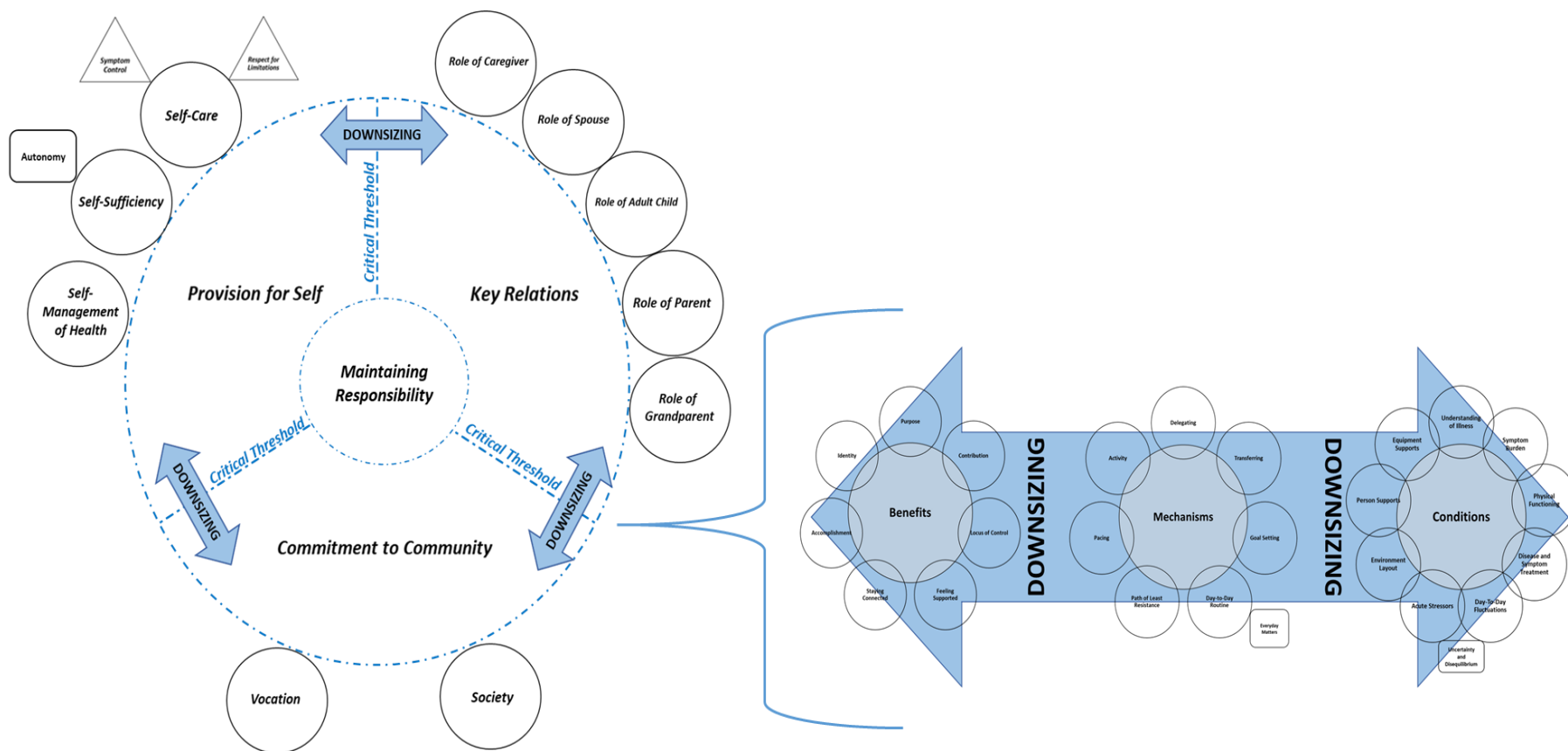


Figure 19: The Grounded Theory of *Maintaining Responsibility*

8.3 The Experience of Activity in People with Advanced Cancer

The aim of this thesis was to gain an in-depth understanding of the experience of activity and quality of life by people with advanced cancer, in order to illuminate the disparity between expressed interest and actual participation in a physical activity intervention, from my previous research in this population (Lowe, Watanabe, Baracos, et al., 2009; Lowe et al., 2013). By following a classic grounded theory approach, what emerged from the empirical data was a complex, multidimensional typology of *maintaining responsibility*, which was the primary explanatory driver underlying the participants' day-to-day behaviour. The participants' focus was not being more active, but rather what activity enabled them to do. Participating in activity was not for its own sake; the day-to-day experience of activity was a reflection of the uniquely defined *critical threshold* of responsibility for each person with advanced cancer.

Maintaining Responsibility contributes a novel perspective on the experience of activity by people with advanced cancer. Of the few qualitative studies examining the experience of physical activity in similar populations, the majority focus on participants attending professionally-supervised exercise interventions (Gulde, Oldervoll, & Martin, 2011; Malcolm et al., 2016; Turner, Tookman, Bristowe, & Maddocks, 2016). In a qualitative study of eleven people with cancer recruited from advanced palliative home care units in Sweden and enrolled in a physiotherapist-supervised physical activity programme, participating in exercise sessions was viewed positively as something to do, and improved energy to do other activities (Gulde et al., 2011). In a phenomenological study of nine people with advanced progressive illness at a London hospice, participating in group exercise class was viewed as having positive effects on their perceptions of hospice, mood and physical functioning (Malcolm et al., 2016). Exercising in a group setting was perceived as having a positive impact on mobility and mood, and positively impacted outlook on the future in a separate phenomenological study of nine people with cancer at a London hospice (Turner et

al., 2016). Across all three studies, participants valued the support and motivation provided by the programme staff, and the opportunity to share their experience of activity with other people in similar circumstances.

Maintaining Responsibility explains how mechanisms, such as activity, are influenced by a combination of perceived benefits and prevailing conditions, such as physical functioning and understanding of illness. 7 of the 11 participants in Gulde et al.'s (2006) study had an Eastern Cooperative Oncology Group (ECOG) Performance Status of 1, which indicates the ability to be ambulatory and to carry out light work, prior to participating in the intervention. None of the studies described the length of survival of the participants, nor did they use clinician-estimated life expectancy as an inclusion criteria. Rates of and reasons for non-participation in these exercise programmes were also not described by the studies (Gulde et al., 2011; Malcolm et al., 2016). Given the association between higher functional status and longer survival in people with cancer (Downing et al., 2007), interest in physical activity could be matched by the ability to participate in a physical activity intervention in those studies.

Most recently, Heywood et al. (2017) conducted a systematic review of sixteen randomized controlled trials and nine prospective observational cohort trials to investigate the safety and feasibility of exercise interventions in patients with advanced cancer. The authors defined advanced cancer as "any cancer that is unlikely to be cured" (p.3032), with no limitation on participant life expectancy; the varying definitions of 'advanced cancer' throughout the literature, however, rendered it challenging for the authors to apply this inclusion criteria. Participants of the included studies were supervised by exercise professionals and able to engage in high intensity interval training. Exercise adherence rates were described in only nine of the reviewed studies, and intervention attrition was described in only eight of the reviewed studies (Heywood, McCarthy, & Skinner, 2017).

Although the authors concluded that exercise interventions appear to be safe and feasible in the included studies, the question remains as to what point during the cancer trajectory these findings would no longer apply. This review did not explore the perceptions and experiences of physical activity in people with advanced cancer.

Maintaining Responsibility emerged from the empirical data of participants with a median survival of 100 days from time of study entry to time of death. In this study, participants were not attending a professionally-supervised physical activity programme; their day-to-day pattern of behaviour was determined by their *critical threshold* of responsibility. Under prevailing conditions of high understanding of illness and low physical functioning, activity was not the means by which participants met their *critical threshold*. At the end of life, participants expended the minimum energy required to fulfil their obligations, and did no more than that. *Maintaining Responsibility* therefore accounts for the incongruence between expressed interest and actual ability of people with advanced cancer to engage in activity.

Not only does *Maintaining Responsibility* explain the day-to-day experience of activity in people with advanced cancer, it bears a number of implications for the objectives of this thesis. In the following sub-sections, the meaning and perceptions of, and barriers and facilitators to, activity in people with advanced cancer are examined in the context of *Maintaining Responsibility*.

8.3.1 The Meaning of Activity for People with Advanced Cancer

The first objective of this thesis was to explore the meaning of activity for people with advanced cancer in the context of their day-to-day life. Participants viewed activity as the day-to-day behaviours which enable them to meet their *critical threshold*. As such, activity was not universally imbued with either positive or negative connotations. Rather than a void in quality of life, the loss of activity can be felt more in terms of the tasks that people with

advanced cancer are no longer able to fulfil. This is congruent with the extant literature: impairment in routine daily activities was more prevalent, and contributed to more distress in people with advanced cancer, than impaired leisure activities (Ruijs et al., 2013). In Reeve et al.'s (2010) study, people with advanced cancer reported a functional, rather than reflexive, account of the individual self: "the emphasis was what might be described as 'functional' – on 'doing' and 'being' – rather than a cognitive process of maintaining meaning" (Reeve et al., 2010, p. 183). *Maintaining Responsibility* unites these findings by proposing that activity holds meaning for people with advanced cancer, insofar as it enables them to meet their *critical threshold*.

Maintaining Responsibility proposes a critical distinction between the meaning of activity for people with advanced cancer, and the positivist-empiricist definitions of physical activity and exercise in the extant literature (as described in section 2.3 of Chapter 2). In this study, participants engaged in activity to meet their *critical threshold* of responsibility, rather than to improve health or well-being. The benefits that emerged from this study (i.e. purpose, contribution, identity, accomplishment, locus of control) were in relation to *maintaining responsibility*, and not participating in activity. Similarly, being more active and improving physical fitness was not the primary motivator of community-dwelling elders in Welmer et al.'s (2012) study. *Maintaining Responsibility* links the meaning of activity for people with advanced cancer, to the prime motive of meeting their *critical threshold* of responsibility.

Parallels can be drawn between the findings of this thesis, and the experience of activity in non-cancer populations. In a qualitative study exploring physical activity in community-dwelling people aged 80-91 years old, participants described the meaning of physical activity as "embedded in everyday activities...[that] were in general viewed as more important than the physical activity itself" (Welmer, Morck, & Dahlin-Lvanoff, 2012, p. 325). Self-perceptions of frailty were high, hence these elderly participants purposefully restricted physical activity

due to fear of falling and inducing pain and fatigue. *Maintaining Responsibility* reveals a similar meaning of everyday activity for people with advanced cancer, and how prevailing conditions, such as high symptom burden and day-to-day fluctuations, can influence the use of activity as a means to meet the *critical threshold* of responsibility.

8.3.2 The Perceptions of Activity by People with Advanced Cancer

The second objective of this thesis was to elicit people with advanced cancer's perceptions of activity with respect to their quality of life. Participants did not perceive activity as the universal means of addressing their main concern, due to the dynamic interplay of perceived benefits and prevailing conditions in influencing *downsizing* to the *critical threshold*. In the face of uncertainty in disease progression and symptom burden, the person with advanced cancer continues on with whatever they are able to manage (McKechnie et al., 2007). Under conditions of high day-to-day fluctuations and low physical functioning, mechanisms involving sedentary behaviour (i.e. pacing and path of least resistance) take precedence for the person with advanced cancer to meet their *critical threshold* of responsibility.

Maintaining Responsibility demonstrates that at any given moment, the person with advanced cancer scales back to the minimum level of responsibility possible in order to conserve energy. Johnston et al. (2012) report that limiting activities was the most common way that people with advanced cancer in the last year of life managed 'overwhelming tiredness' (Johnston et al., 2012, p. 1625). Reeve et al. (2010) describe the 'felt exhaustion' of people with advanced cancer preceding periods of biographical upset, during which they have insufficient energy levels to complete daily activities; there is a need to restore depleted energy in order to sustain the continuity of the daily routine (Reeve et al., 2010, p. 190). Depending upon prevailing conditions, activity can be perceived by people with advanced cancer as obstructive to meeting their *critical threshold* of responsibility.

The findings of this thesis draw parallels to the perceptions of activity in non-cancer populations. In a qualitative study of African Americans with Class III/IV heart failure, the theme of “given up” emerged from participant narratives of current physical activity. Despite an expressed desire to be physically active, one person with advanced stage cardiac failure reported “ ‘I don’t really do nothing now. I just do things for myself, just for me...I never lost interest. But I just can’t do it no more’ ” (McCarthy, Katz, Schipper, & Dickson, 2015, p. 979). Participant narratives of their typical day showed very little activity, which was attributed to the low level of physical functioning and conditioning consistent with advanced stage cardiac failure. *Maintaining Responsibility* explains that, under the condition of low physical functioning, people with advanced cancer likewise prioritise their most essential responsibilities at that point in time, and do no more than that.

8.3.3 Barriers and Facilitators to Activity for People with Advanced Cancer

The third objective of this thesis was to elicit people with advanced cancer’s views of barriers and facilitators to activity in the context of their day-to-day life. In this study, the ability of participants to engage in activity varied with the changing conditions of *maintaining responsibility*. *Maintaining Responsibility* explains the state of flux of the *critical threshold*, due to the multifaceted interaction between perceived benefits, prevailing conditions, and mechanisms which influence *downsizing*. The prevailing conditions of understanding of illness, symptom burden, acute stressors and person supports can impede or facilitate activity on a day-to-day basis.

For participants in this study, disease can be perceived as separate from the self, and affected their ability to engage in activity on a day-to-day basis. The person with advanced cancer can experience the disembodiment of cancer, which is perceived as a constant threat to bodily integrity, and which limits the ability to do the things they want to do (McKechnie et al., 2007). The physical body is experienced as letting the person with advanced cancer

down, and the ways in which the physical body is affected by the disease process and treatment determined how they lived. Reeve et al. (2010) describe how advanced cancer imposes an embodied cost, in the form of fatigue and energy depletion, to individual efforts to maintain continuity of daily routine. Cancer is described as having an embodied, rather than cognitive, effect: as one person with advanced cancer reported, “*‘It drains you...I feel with my cancer, it’s hard work.’*” (Reeve et al., 2010, p. 188). Perceived as a physical adversary, disease burden can be a barrier to activity in people with advanced cancer.

Awareness of the implications of disease burden can have the opposite effect on people with advanced cancer. *Maintaining Responsibility* identifies knowledge of disease progression and awareness of prognosis as a condition which influences *downsizing* to the *critical threshold* of responsibility. Although activity levels were low, participants in this study were able to engage in the everyday activity that the understanding of their illness permitted. In a study of people with advanced cancer in the last year of life in Scotland, acceptance of disease progression and prognosis enabled participants to self-manage their illness more effectively (Johnston et al., 2012). Within the domain of living life fully, appraisal of new knowledge leads to people with advanced cancer letting go of what is extraneous (Lethborg et al., 2006). Thus understanding of illness, a condition of *maintaining responsibility*, can be a facilitator to activity in people with advanced cancer.

Symptom burden, a condition of *maintaining responsibility*, can be a barrier to activity in people with advanced cancer. In this study, participants felt both the physiological and psychological impact of symptom burden on their everyday activity. Ruijs et al. (2013) report that in the domain of medical symptoms, weakness was present in 93% (n=56), and deemed unbearable in 57% (n=34) of people with advanced cancer; tiredness was present in 87% (n=52), and deemed unbearable in 35% (n=21), of people with advanced cancer. More than pain or dyspnoea, weakness and tiredness contributed the most to the suffering of people

with advanced cancer and would impact their ability to do things (McKechnie et al., 2007).

Maintaining Responsibility elucidates symptom burden as a condition which influences *downsizing* to meet the *critical threshold*, and which impedes participants' ability to engage in activity.

Acute stressors, a condition of *maintaining responsibility*, can be an immediate barrier to activity in people with advanced cancer. Participants in this study expressed feeling incapacitated after the onset of acute physical stressors (i.e. hospitalization) or acute psychosocial stressors (i.e. breaking bad news). Within the domain of experiencing the reality of cancer, new stressors arise throughout the advanced cancer experience that can set off disequilibrium for the individual (Lethborg et al., 2006). Reeve et al. (2010) report that transient periods of turbulent flow are associated with disruptive events in the participant's biographical narrative, and which may be exhaustive in terms of their cumulative impact on individual capacity. *Maintaining Responsibility* explains acute stressors as a condition which influences *downsizing* to the *critical threshold*, and which impedes the ability of people with advanced cancer to engage in activity.

Person supports, a condition of *maintaining responsibility*, can facilitate activity in people with advanced cancer. Reeve et al. (2010) assert that during periods of biographical fracture, the availability of supports aids the person with advanced cancer's capacity to manage their day-to-day matters. Johnston et al. (2012) concur on the need of people with advanced cancer in the last year of life to draw upon the physical and emotional support from others to remain independent and at home. Within the domain of responding to the impact of cancer, people with advanced cancer revise their beliefs such that they are able to see others as legitimate sources of care and support (Lethborg et al., 2006). Availability, access and proximity to family, friends and the health care team can facilitate activity as a mechanism to address their main concern.

Parallels can be drawn between the findings of this thesis, and barriers to physical activity in non-cancer populations. In a review of physical activity interventions in people with end-stage renal disease on dialysis, Bohm et al. (2010) identify a number of barriers to exercise participation, including frequent changes in clinical status, variability in physical functioning, and post-dialysis fatigue. The low recruitment and high attrition rates in physical activity intervention trials have been attributed to high morbidity and mortality rates in people with end-stage renal disease (Bohm, Ho, & Duhamel, 2010). *Maintaining Responsibility* explains the similar disparity between expressed interest and actual participation in activity by people with advanced cancer, due to the dynamic interplay of perceived benefits and prevailing conditions that influence *downsizing* to the *critical threshold*. In both advanced cancer and end-stage renal populations, there is uncertainty as to the timepoint in the disease trajectory before which barriers to participation in physical activity intervention are minimized.

8.4 Evaluating *Maintaining Responsibility*

Maintaining Responsibility is an integrated set of conceptual relationships that is systematically generated from empirical data, and which explains the main concern of people with advanced cancer, and how it is managed. Classic grounded theory is unique in its intent towards discovery and emergent understanding, rather than testable theory. As such, O'Connor et al. (2008) argue that the most appropriate standards for evaluating distinct methodology are those that are proposed by its originators (O'Connor, Netting, & Thomas, 2008). Glaser's (1992) four criteria of fit, workability, relevance and modifiability were applied in order to evaluate *Maintaining Responsibility*.

8.4.1 *Fit*

The criterion of *fit* questions whether the concept adequately expresses the pattern in the data which it intends to conceptualize (Glaser, 1992). *Fit* was enhanced by my iterative use

of constant comparative analysis, as detailed in the step-by-step process of conceptual development in Chapter 4. *Maintaining Responsibility* bears witness to the criterion of *fit*, and fidelity to a classic grounded theory approach: the core conceptual category could not have been anticipated *a priori*, and the resulting theory was not constructed to match the initial aims and objectives of this thesis.

8.4.2 Work

The criterion of *work* questions whether the concepts and proposed conceptual relationships sufficiently explain the behaviour in a substantive area and account for how the main concern of participants is resolved (Glaser, 1992). My close adherence to a classic grounded theory approach throughout the conduct of this thesis, including the abeyance of the literature review, has ensured that the emergent concepts stayed true to the latent pattern of behaviour of the participants under study and were not based on preconceptions. *Maintaining Responsibility* reflects the criterion of *work*, in that it integrated distinct concepts of responsibility from disparate studies of people with advanced cancer in the literature review, into the unified theory.

8.4.3 Relevance

The criterion of *relevance* questions whether the theory being conceptually grounded in the data is reflective of the significance of the participants' main concern (Glaser, 1992). *Relevance* is demonstrated by concepts which "evoke instant grab" in that they capture the importance of the what is actually occurring in the substantive area under study (Holton & Walsh, 2017, p. 155). The analytic questions that I used to interrogate the data, as detailed in Chapter 4, ensured the *relevance* of *Maintaining Responsibility* to the participants' main concern. The core conceptual category of *Maintaining Responsibility* likewise resonates with my and other colleagues' experiences working with people with advanced cancer, in both the clinical and research setting.

8.4.4 Modifiability

The criterion of *modifiability* is specific to the propositional nature of classic grounded theory, and questions the openness of theory to being modified as new data is constantly compared to generate new categories, properties and dimensions (Glaser, 1992).

Maintaining Responsibility bears witness to modifiability in that the literature review (presented in Chapter 7) yielded new sub-categories, and further articulated properties and dimensions, which were integrated into the final theory.

8.5 Reflections on the Research Process

Reflexivity encompasses the researcher's continuous, active reflection throughout all stages of the research process, which is influenced by the researcher's own values and beliefs (Carter & Henderson, 2005). As the researcher is the primary instrument in qualitative research (Snape & Spencer, 2003), my previous positivist-empiricist stance and positive assumptions regarding physical activity were the context from which my role as the primary instrument evolved. The impetus of this thesis was to explain the incongruence between expressed interest in physical activity, and actual participation in a physical activity intervention by people with advanced cancer (Lowe, Watanabe, Baracos, et al., 2009; Lowe et al., 2010, 2013). Following an epistemic-ontological paradigm shift, I embraced classic grounded theory as a methodology to access the reality of day-to-day activity from the perspective of people with advanced cancer.

The challenge of classic grounded theory lies in setting aside pre-conceived professional ideas and remaining open to what emerges as the main concern for study participants (Holton & Walsh, 2017). In our discussion at the Grounded Theory Institute, Dr. Glaser contends that doing classic grounded theory is most difficult for those who have clinical or research experience in the substantive area of interest (B. Glaser, personal communication). Despite the occasional discomfort I felt in diverging from my professional area of research

interest, I stayed open to what emerged from the data, and trusted in the emergence of theory to follow it through to the conclusion. *Maintaining Responsibility* would not have resulted had it not been for adherence to classic grounded theory methodology and procedures.

As the primary research instrument, I recognize my own influence on the theoretical framework which emerged from the empirical data of this study. Although I tried to keep as close as possible to the empirical data when naming concepts, my selection of terminology may not be congruent with how another researcher would conceptualize the same categories. Two different researchers studying a similar population, for example, can yield two distinct grounded theories (Barello et al., 2015; Barton-Caro, 2015). It is therefore possible that the literature review search terms were not reflective of all the possible names that could be ascribed to the same core conceptual category; hence studies relevant for inclusion in the literature review may have been missed. To obviate this possibility, however, the scope of the literature review was kept as wide as possible.

Finally, the selection of classic grounded theory methodology may be precluded by pragmatic issues. This study's adherence to a classic grounded theory approach, including the iterative process of concurrent data collection, constant comparative analysis and theoretical sampling and the abeyance of the literature review, required a prolonged period of time. The wide and inclusive scope of the literature review, including the screening of nearly 4000 studies by myself, was time and resource intensive. Rigorous adherence to classic grounded theory methodology may not be possible for a researcher who is also engaged in full-time clinical practice.

8.6 Summary

Chapter 8 presented *Maintaining Responsibility*, the grounded theory that emerged from this study of activity in people with advanced cancer. *Maintaining Responsibility* explains the

day-to-day experience of activity as a reflection of the uniquely defined *critical threshold* for each person with advanced cancer. Activity holds meaning for people with advanced cancer, insofar as it enables them to meet their *critical threshold*. People with advanced cancer do not perceive activity as the universal mechanism of *maintaining responsibility*, due to the dynamic interplay of perceived benefits and prevailing conditions in influencing *downsizing*. The prevailing conditions of *maintaining responsibility* (i.e. understanding of illness, symptom burden, acute stressors and person supports) can impede or facilitate activity on a day-to-day basis. *Maintaining Responsibility* demonstrates the criteria of fit, work, relevance and modifiability. Reflexivity on the classic grounded theory approach to the research process was considered.

The conclusions to the thesis, contributions to knowledge, implications for research and clinical practice, and evaluation of study limitations and strengths will follow in Chapter 9.

Chapter 9 – Conclusions to the thesis, contributions to knowledge, implications for research and clinical practice, and evaluation of study limitations and strengths

9.1 Introduction

This chapter presents a number of conclusions from this thesis, and from the grounded theory of *Maintaining Responsibility*. The first section summarises conclusions to the empirical findings. In the second section, the study's contributions to knowledge, recommendations for research, and implications for practice are addressed. Finally, study limitations and strengths are presented and assessed.

9.2 Conclusions of Empirical Findings

The day-to-day pattern of behaviour for people with advanced cancer is primarily motivated by the duties, obligations and tasks which are incumbent upon them to fulfil. Their main concern is to meet their minimum level of responsibility, which is a dynamic state that is uniquely defined by each individual. For some, the minimum level of responsibility entails just doing what they need to in order to exist; this may include the obligation to care for themselves, to advocate for their personal well-being, and to be able to manage independently. For others, the minimum level of responsibility may entail personal obligations, such as those associated with family and household roles, or community obligations, such as those attributed to vocation or to society.

The minimum level of responsibility can be influenced by one or more conditions, including the understanding of illness, symptom burden, physical functioning, disease and symptom treatment strategies, day-to-day fluctuations, acute stressors, environmental layout and supports. Meeting the minimum level of responsibility can result in one or more benefits

(purpose, contribution, accomplishment, identity, locus of control, staying connected and feeling supported) for the person with advanced cancer. Each individual evaluates the benefits of maintaining responsibility against the prevailing conditions, in order to determine the minimum level of responsibility which needs to be met at that moment in time.

The minimum level of responsibility can be met by one or more mechanisms, including delegating, transferring, goal-setting, day-to-day routine, the path of least resistance, pacing, and activity. Activity is one of many potential mechanisms to maintain responsibility. In the context of the day-to-day behaviour of people with advanced cancer, their experience of activity is focused on what it enables them to do. People with advanced cancer participate in activity that enables them to meet their minimum level of responsibility. Meeting the minimum level of responsibility, rather than being more active, is the issue of most importance to the person with advanced cancer.

9.3 Contributions to Knowledge and Theory

Grounded theory has the potential to yield novel insights about old problems, and may open up entirely new areas for investigation (Holton & Walsh, 2017). *Maintaining responsibility* explains the incongruence between expressed interest and actual participation in a physical activity intervention by people with advanced cancer. Engaging in activity, in and of itself, is not the primary motivator underlying the day-to-day behaviour of people with advanced cancer. Activity is as one potential mechanism which enabled participants to manage their main concern of *maintaining responsibility*. People with advanced cancer participate in activity insofar as it enables them to meet their *critical threshold* of duties and obligations to others.

Maintaining responsibility represents a novel contribution to theory. As shown by the literature review in Chapter 7, there is no extant theoretical framework of responsibility in people with advanced cancer. Despite differing aims and objectives, empirical studies in

people with advanced cancer highlight separate elements related to responsibility. Previous studies have described activities of daily living and functioning of people with advanced cancer, but none have explored the reasons underlying their behaviour. The power of grounded theory lies in its integration of these distinct concepts into a unified theoretical framework guided by the central tenet of *maintaining responsibility*.

This thesis represents a novel contribution to methodology. This thesis proffers a rigorous literature review method that is congruent with a classic grounded theory approach, and that has not been previously described. Accelerometers, such as the *activPAL™* activity monitor, are considered the gold standard of quantitative assessment in physical activity research (Gorman et al., 2014). Rather than for statistical analysis of quantitative data, the activity monitor output was used as a qualitative probe to reveal the individual's pattern of day-to-day behaviour, and to explore the reasons underlying those patterns with the participant. To our knowledge, this study is the first to utilize an accelerometer within a qualitative methodology in people with advanced cancer.

9.4 Implications for Research in Activity and Advanced Cancer

The impetus for this thesis was to explain the discrepancy between expressed interest and actual participation in a physical activity intervention from my previous research in people with advanced cancer (Lowe, Watanabe, Baracos, et al., 2009; Lowe et al., 2010, 2013).

Maintaining Responsibility illustrated the incongruence between my professional area of research interest, and the main concern of participants under study. Expressed interest in physical activity was a confirmation of shared positive assumptions about physical activity, rather than a reflection of the underlying motivations and day-to-day experience of people with advanced cancer. The assumptions with which the researcher approaches the research problem and method, may impact study outcomes (Craig et al., 2008); the predominantly

positivist-empiricist assumptions underlying physical activity research in different populations need to be examined.

Activity is important to people with advanced cancer, but not through the positivist-empiricist lens which is used predominantly in the extant literature. Participants view activity as the day-to-day behaviour which enables them to meet their *critical threshold* of responsibility, rather than as a means of improving health and fitness. Any level of physical exertion may be all that the person with advanced cancer is able to undertake. As such, testing exercise interventions using objective fitness measures are not appropriate in people with advanced cancer and a life expectancy of less than four months. Future research should explore how one can modify barriers and enhance facilitators to everyday activity in this population, using concepts that emerged from, and nomenclature that is aligned with, the advanced cancer experience. Meeting the *critical threshold* of responsibility, as uniquely defined by the individual, may be the most pertinent evaluable outcome measure.

In a discussion of physical activity research in persons with disabilities, Wheeler (1998) argues that “we must consider the context in which we collect our data, what our work means to the subjects, and the value judgements that are routinely made in the questions that researchers ask and the methods they use to find the answers” (Wheeler, 1998, p. 245). In this thesis, qualitative inquiry was guided by exploration of participants’ perceptions of activity, alongside their day-to-day behaviour. Although the use of classic grounded theory approach was fundamental to the emergence of *Maintaining Responsibility*, one cannot dismiss the previous quantitative research which served as the catalyst for the research problem. Both positivist and interpretivist approaches, and quantitative and qualitative methodologies, are clearly warranted in future research in activity and advanced cancer.

Maintaining Responsibility reveals a new research problem of determining how one can assist people with advanced cancer in addressing their main concern. The design of future

interventions, therefore, should focus on *maintaining responsibility*, and the dynamic interplay of benefits, conditions and mechanisms which enable the *critical threshold* to be met. Rather than modifying activity levels, future interventions should examine how people with advanced cancer can manage day-to-day fluctuations, for example, so as to facilitate their ability to meet the *critical threshold*. Future research should explore how to enhance supports that will enable the person with advanced cancer to engage in everyday activity for as long as possible. *Maintaining Responsibility* proposes that the *critical threshold* is uniquely defined by each person with advanced cancer; as such, a “one size fits all” approach does not apply. The development of future quality-of-life interventions should be focused on the participant’s main concern, and tailored to the individual participant.

9.5 Implications for Clinical Practice

The findings of this thesis bear a number of implications for clinical practice. *Maintaining Responsibility* emerged from the advanced cancer experience, and the meaning of activity is unique for people with advanced cancer. The language and constructs of activity which clinicians use may not be congruent with how activity is experienced by people with advanced cancer. The issues of greatest importance to people with advanced cancer may not be the same for interdisciplinary team members who are involved in their clinical care. Clinicians should focus on supporting, and being aware of the barriers and facilitators to, everyday activity of people with advanced cancer.

This behoves interdisciplinary team members to take the time to explore these issues with the person with advanced cancer, and to solicit the individual’s perspective whenever possible. Interdisciplinary team members should pay close attention to, and actively question the underlying reasons for, individual patterns of behaviour. Interdisciplinary team members should monitor for changes in the individual clinical context, as this can lead to changes in which issues are prioritized by the person with advanced cancer. When

considering potential interventions to improve quality of life, interdisciplinary team members should provide opportunities for people with advanced cancer to learn about potential benefits and risks, discuss their perceptions and experiences, and to ask questions and reflect upon the information that was shared. When possible, decisions about care should be made jointly between people with advanced cancer and their interdisciplinary care team, and should be focused on those priorities which are uniquely defined by the individual.

9.6 Study Limitations

A substantive theory of *Maintaining Responsibility* emerged from this thesis of activity and people with advanced cancer. As all participants were recruited from an outpatient palliative care department at a tertiary cancer centre in Alberta, Canada, the scope of *Maintaining Responsibility* is limited to the chosen site and population. In order to increase its scope to that of a middle range theory, substantive formalization is required and would entail sampling different substantive groups, contexts, and social units (Holton & Walsh, 2017). Future research should examine people with advanced cancer within different care settings, across Canada, or in different countries, as data for constant comparative analysis for the grounded theory.

Classic grounded theory methods can be applied to any type of empirical data, thereby enriching the theoretical framework that emerges therefrom (B. Glaser, 1999). This thesis yielded quantitative *activPAL*[™] activity monitor data which has not been analysed due to time and resource constraints, and which have not been included in the thesis due to the word limit. Future research should consider applying classic grounded theory approach to the quantitative *activPAL*[™] activity monitor data in order to elaborate and expand upon the grounded theory.

All of the study participants were aware of the progressive, incurable nature of their disease and its prognostic implications. Had time and resources permitted, further theoretical sampling could have explored how lack of awareness and acceptance of death impacts *maintaining responsibility* in people with advanced cancer. External expectations and cultural considerations were described by some of the included studies in the literature review, but did not emerge from the empirical data of this thesis. Further theoretical sampling is required to determine how external expectations and cultural considerations influence *downsizing* to the *critical threshold* of responsibility, and potentially modify the grounded theory.

9.7 Study Strengths

A number of strengths are worthy of mention in this thesis. This study was rigorous in its adherence to classic grounded theory methodology throughout the study design, data collection, data analysis, literature review and writing processes. The two-phase study design, and use of the activity monitor output and daily record sheets as qualitative probes in the semi-structured interviews, allowed for rich data to be collected and an original theory to emerge. *Maintaining Responsibility* provides an in-depth understanding of the experience of day-to-day behaviour of people with advanced cancer, and comprehensively explains the disparity between expressed interest and actual participation in activity in this population.

Data immersion was thorough in that I repeatedly listened to each recording, transcribed each interview, and recurrently reviewed each transcript, activity monitor output and daily record sheet myself. This study was rigorous in its iterative approach to concurrent data collection, constant comparative analysis and theoretical sampling, thus rendering it possible to achieve theoretical saturation. The process of conceptual development, as detailed in Chapter 4, was robust and comprehensive; nearly all of the theoretical codes were hand-

sorted into conceptual categories, and the majority of data are represented in the grounded theory. The same detailed process of conceptual development was undertaken for the literature review, which was all-inclusive and exhaustive in terms of its scope.

Maintaining Responsibility is supported by existing claims in the extant literature, and contributes new claims to the area of activity in people with advanced cancer. *Maintaining responsibility* emerged as the main concern of participants in this study, and is the conceptual foundation upon which the grounded theory is based. In the extant literature, elements of responsibility appear in studies with differing aims and objectives; this thesis is the first to unite these concepts and their inter-relationships in an integrated theoretical framework. While the grounded theory emerged from this study of people with advanced cancer recruited from an outpatient palliative department in a tertiary cancer centre in Canada, its theoretical propositions may be applicable to other end of life populations, and in other settings. Extant studies have likewise indicated that concepts related to responsibility may be present across different cultures, which would be worthy of future theoretical sampling.

9.8 Final Conclusion

Maintaining responsibility is the primary underlying motivation for the day-to-day behaviour of people with advanced cancer. The *critical threshold*, or minimum level of responsibility to be met, is a dynamic state that is uniquely determined by the individual with advanced cancer. The *critical threshold* can encompass obligations to oneself, to one's family and household, or to one's vocation or the society at large. The individual with advanced cancer *downsizes*, or scales back to their *critical threshold*, according to the combination of potential benefits and prevailing conditions at any given moment in time. The dynamic interplay of benefits and conditions also influences the use of different mechanisms, including activity, in order to meet the minimum level of responsibility.

People with advanced cancer experience activity as the day-to-day behaviours which enable them to fulfil the obligations that they deem most important. People with advanced cancer perceive activity as one possible means of meeting their minimum level of responsibility. Their ability to engage in activity, however, is limited by varying conditions at any given moment in time. Symptom burden, day-to-day fluctuations and acute stressors modify the *critical threshold* and are barriers to activity. Expressed interest is therefore not matched by the ability to engage in activity by people with advanced cancer.

Activity is important to people with advanced cancer, but not for its own sake. Activity is meaningful to people with advanced cancer insofar as it enables them to meet their minimum level of responsibility. The meaning of activity for people with advanced cancer is incongruent with the positivist-empiricist construct of physical activity. Future studies should examine how best to minimize barriers, and facilitate mechanisms with respect to the main concern of *maintaining responsibility* in people with advanced cancer.

Through adherence to classic grounded theory methodology, this original grounded theory emerged that is aligned with the advanced cancer experience. *Maintaining Responsibility* should inform research and clinical practice by focussing on the issues of greatest importance to the individual, and which may ultimately impact quality of life for people with advanced cancer.

References

- Agteresch, H. J., Dagnelie, P. C., van der Gaast, A., Stijnen, T., & Wilson, J. H. (2000). Randomized clinical trial of adenosine 5'-triphosphate in patients with advanced non-small-cell lung cancer. *J Natl Cancer Inst*, 92(4), 321-328.
- Alberta. (2016). Alberta Health Information Act. Retrieved from <http://www.qp.alberta.ca/documents/Acts/H05.pdf>
- Albrecht, T. A., & Taylor, A. G. (2012). Physical Activity in Patients With Advanced-Stage Cancer: A Systematic Review of the Literature. *Clinical Journal of Oncology Nursing*, 16(3), 293-300. doi:10.1188/12.cjon.293-300
- Allemani, C., Weir, H. K., Carreira, H., Harewood, R., Spika, D., Wang, X. S., . . . Coleman, M. P. (2015). Global surveillance of cancer survival 1995-2009: analysis of individual data for 25,676,887 patients from 279 population-based registries in 67 countries (CONCORD-2). *Lancet*, 385(9972), 977-1010. doi:10.1016/s0140-6736(14)62038-9
- Allsopp, J. (2013). Competing paradigms and health research: design and process *Researching Health: Qualitative, Quantitative and Mixed Methods* (pp. 18-41): SAGE.
- Anderson, F., Downing, G. M., Hill, J., Casorso, L., & Lerch, N. (1996). Palliative performance scale (PPS): a new tool. *J Palliat Care*, 12(1), 5-11.
- Andrews, P. L. R., Morrow, G. R., Hickok, J. T., & al., e. (2004). Mechanisms and models of fatigue associated with cancer and its treatment: evidence of pre-clinical and clinical studies. In M. K. J. Armes, I. Higginson (Ed.), *Fatigue in Cancer* (pp. 51-87). Oxford: Oxford University Press.
- Axelsson, B., & Sjoden, P. O. (1998). Quality of life of cancer patients and their spouses in palliative home care. *Palliat Med*, 12(1), 29-39. doi:10.1191/026921698676629560
- Barello, S., Graffigna, G., Vegni, E., Savarese, M., Lombardi, F., & Bosio, A. C. (2015). 'Engage me in taking care of my heart': a grounded theory study on patient-cardiologist relationship in the hospital management of heart failure. *BMJ Open*, 5(3), e005582. doi:10.1136/bmjopen-2014-005582
- Bartlett, D., & Payne, S. (1997). Grounded Theory - its basis, rationale and procedures. In G. McKenzie, J. Powell, & R. Usher (Eds.), *Understanding social research : perspectives on methodology and practice* (pp. 173-195). London: Falmer Press.
- Barton-Caro. (2015). Embodied Revelation: A Classic Grounded Theory of Heart Failure Patient Decision Making Surrounding Primary Prevention Implantable Cardioverter Defibrillator Therapy. *Grounded Theory Review*, 14(2).
- Beaton, R., Pagdin-Friesen, W., Robertson, C., Vigar, C., Watson, H., & Harris, S. R. (2009). Effects of exercise intervention on persons with metastatic cancer: a systematic review. *Physiother Can*, 61(3), 141-153. doi:10.3138/physio.61.3.141
- Bohm, C. J., Ho, J., & Duhamel, T. A. (2010). Regular physical activity and exercise therapy in end-stage renal disease: how should we move forward? *J Nephrol*, 23(3), 235-243.
- Bouchard, C., & Shephard, R. J. (1994). Physical activity, fitness and health: the model and key concepts. In C. Bouchard, R. J. Shephard, & T. Stephens (Eds.), *Physical activity, fitness and health - International proceedings and consensus statement* (pp. 77-88). Champaign, IL: Human Kinetics.
- Bower, J. E., Ganz, P. A., Aziz, N., & Fahey, J. L. (2002). Fatigue and proinflammatory cytokine activity in breast cancer survivors. *Psychosom Med*, 64(4), 604-611.
- Bragaru, M., van Wilgen, C. P., Geertzen, J. H. B., Ruijs, S., Dijkstra, P. U., & Dekker, R. (2013). Barriers and Facilitators of Participation in Sports: A Qualitative Study on Dutch

- Individuals with Lower Limb Amputation. *Plos One*, 8(3), 9.
doi:10.1371/journal.pone.0059881
- Canada, P. o. (2014). CHARLIE ANGUS - PRIVATE MEMBERS' MOTIONS - 41ST PARLIAMENT, 2ND SESSION. Retrieved from
[http://www.ourcommons.ca/Parliamentarians/en/members/Charlie-Angus\(25470\)/Motions?documentId=6261234](http://www.ourcommons.ca/Parliamentarians/en/members/Charlie-Angus(25470)/Motions?documentId=6261234)
- Carter, S., & Henderson, L. (2005). Approaches to qualitative data collection in social science *Handbook of Health Research Methods: Investigation, Measurement and Analysis* (pp. 216-229). Maidenhead: Open University Press.
- CCS. (2016). Right to Care: Palliative Care for All Canadians. Retrieved from
<https://www.cancer.ca/~media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en>
- CCS. (2017). Canadian Cancer Statistics 2017. Retrieved from
<http://www.cancer.ca/~media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2017-EN.pdf?la=en>
- Cella, D. F. (1994). QUALITY-OF-LIFE - CONCEPTS AND DEFINITION. *Journal of Pain and Symptom Management*, 9(3), 186-192. doi:10.1016/0885-3924(94)90129-5
- Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. Thousand Oaks: Sage.
- Conrad, R., Mucke, M., Marinova, M., Burghardt, A., Stieber, C., Cuhls, H., & Radbruch, L. (2017). Measurement of Quality of Life in Palliative Care: Evidence for Criterion-Oriented Validity of a Single-Item Approach. *J Palliat Med*, 20(6), 604-610.
doi:10.1089/jpm.2016.0218
- Courneya, K. S., & Friedenreich, C. M. (2007). Physical activity and cancer control. *Semin Oncol Nurs*, 23(4), 242-252. doi:10.1016/j.soncn.2007.08.002
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *Bmj*, 337, a1655. doi:10.1136/bmj.a1655
- Crum, R. M., Anthony, J. C., Bassett, S. S., & Folstein, M. F. (1993). Population-based norms for the Mini-Mental State Examination by age and educational level. *Jama*, 269(18), 2386-2391.
- Curt, G. A., Breitbart, W., Cella, D., Groopman, J. E., Horning, S. J., Itri, L. M., . . . Vogelzang, N. J. (2000). Impact of cancer-related fatigue on the lives of patients: new findings from the Fatigue Coalition. *Oncologist*, 5(5), 353-360.
- Denzin, N. K., & Lincoln, Y. S. (2011). Introduction - The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research* (4th ed., pp. 1-19). Thousand Oaks: Sage.
- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., . . . Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6, 35-13.
doi:10.1186/1471-2288-6-35
- Downing, M., Lau, F., Lesperance, M., Karlson, N., Shaw, J., Kuziemy, C., . . . Casarett, D. (2007). Meta-analysis of survival prediction with Palliative Performance Scale. *J Palliat Care*, 23(4), 245-252; discussion 252-244.
- Eismann, E. A., Lush, E., & Sephton, S. E. (2010). Circadian effects in cancer-relevant psychoneuroendocrine and immune pathways. *Psychoneuroendocrinology*, 35(7), 963-976. doi:10.1016/j.psyneuen.2009.12.011
- Elliott, J. A., & Olver, I. N. (2007). Hope and hoping in the talk of dying cancer patients. *Social Science & Medicine*, 64(1), 138-149. doi:10.1016/j.socscimed.2006.08.029
- Engward, H. (2013). Understanding grounded theory. *Nursing standard (Royal College of Nursing (Great Britain) : 1987)*, 28(7), 37-41. doi:10.7748/ns2013.10.28.7.37.e7806

EZPCP. (2016). Edmonton Zone Palliative Care Program Annual General Meeting Annual Report 2015-2016

Retrieved from

http://www.palliative.org/NewPC/_pdfs/reports/EZPCP%20Cross%20Sites%20Report%20Sept%2014%202016.pdf

- Fairchild, A., Pituskin, E., Rose, B., Ghosh, S., Dutka, J., Driga, A., . . . Severin, D. (2009). The rapid access palliative radiotherapy program: blueprint for initiation of a one-stop multidisciplinary bone metastases clinic. *Support Care Cancer*, 17(2), 163-170. doi:10.1007/s00520-008-0468-3
- Ferreira, M. L., Sherrington, C., Smith, K., Carswell, P., Bell, R., Bell, M., . . . Vardon, P. (2012). Physical activity improves strength, balance and endurance in adults aged 40-65 years: a systematic review. *Journal of Physiotherapy*, 58(3), 145-156.
- Fidler, M. M., Bray, F., & Soerjomataram, I. (2017). The global cancer burden and human development: A review. *Scand J Public Health*, 1403494817715400. doi:10.1177/1403494817715400
- Fong, D. Y. T., Ho, J. W. C., Hui, B. P. H., Lee, A. M., Macfarlane, D. J., Leung, S. S. K., . . . Cheng, K. K. (2012). Physical activity for cancer survivors: meta-analysis of randomised controlled trials. *British Medical Journal*, 344, 14. doi:10.1136/bmj.e70
- Friese, S. (2016). Computer-Assisted Grounded Theory Analysis. In C. Equit & C. Hohage (Eds.), *Handbuch Grounded Theory - Von der Methodologie zur Forschungspraxis* (pp. 483-507). Weinheim: Beltz Juventa.
- Giesinger, J. M., Wintner, L. M., Oberguggenberger, A. S., Gamper, E. M., Fiegl, M., Denz, H., . . . Holzner, B. (2011). Quality of life trajectory in patients with advanced cancer during the last year of life. *J Palliat Med*, 14(8), 904-912. doi:10.1089/jpm.2011.0086
- Gilbertson-White, S., Aouizerat, B. E., Jahan, T., & Miaskowski, C. (2011). A review of the literature on multiple symptoms, their predictors, and associated outcomes in patients with advanced cancer. *Palliative & Supportive Care*, 9(1), 81-102. doi:10.1017/s147895151000057x
- Glare, P. A. (2013). Early implementation of palliative care can improve patient outcomes. *J Natl Compr Canc Netw*, 11 Suppl 1, S3-9.
- Glaser. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser. (1992). *Basics of grounded theory analysis: emergence vs. forcing*. Mill Valley, CA: Sociology Press.
- Glaser. (1998). *Doing Grounded Theory: issues and discussions*. Mill Valley: Sociology Press.
- Glaser. (2002). Conceptualization: On Theory and Theorizing Using Grounded Theory. *International Journal of Qualitative Methods*, 1(2), 1-31.
- Glaser, & Strauss. (1967). *The discovery of grounded theory: strategies for qualitative research*. New York: Aldine de Gruyter.
- Glaser, B. (1999). The future of grounded theory. *Qualitative Health Research*, 9(6), 836-845. doi:10.1177/104973299129122199
- Goldenberg, M. J. (2006). On evidence and evidence-based medicine: Lessons from the philosophy of science. *Social Science & Medicine*, 62(11), 2621-2632. doi:10.1016/j.socsimed.2005.11.031
- Goldstein, M., Houtepen, R., Proot, I. M., Abu-Saad, H. H., Spreeuwenberg, C., & Widdershoven, G. (2006). What is a good death? Terminally ill patients dealing with normative expectations around death and dying. *Patient Educ Couns*, 64(1-3), 378-386. doi:10.1016/j.pec.2006.04.008
- Gorman, E., Hanson, H. M., Yang, P. H., Khan, K. M., Liu-Ambrose, T., & Ashe, M. C. (2014). Accelerometry analysis of physical activity and sedentary behavior in older adults: a systematic review and data analysis. *Eur Rev Aging Phys Act*, 11, 35-49. doi:10.1007/s11556-013-0132-x

- Gulde, I., Oldervoll, L. M., & Martin, C. (2011). Palliative Cancer Patients' Experience of Physical Activity. *Journal of Palliative Care*, 27(4), 296-302.
- Haun, M. W., Estel, S., Rucker, G., Friederich, H. C., Villalobos, M., Thomas, M., & Hartmann, M. (2017). Early palliative care for adults with advanced cancer. *Cochrane Database Syst Rev*, 6, Cd011129. doi:10.1002/14651858.CD011129.pub2
- Hawryluck, L. (2004). People at the end of life are a vulnerable research population. *Clin Oncol (R Coll Radiol)*, 16(3), 225-226.
- Heywood, R., McCarthy, A. L., & Skinner, T. L. (2017). Safety and feasibility of exercise interventions in patients with advanced cancer: a systematic review. *Support Care Cancer*. doi:10.1007/s00520-017-3827-0
- Ho, A. H., Leung, P. P., Tse, D. M., Pang, S. M., Chochinov, H. M., Neimeyer, R. A., & Chan, C. L. (2013). Dignity amidst liminality: healing within suffering among Chinese terminal cancer patients. *Death Stud*, 37(10), 953-970. doi:10.1080/07481187.2012.703078
- Holton, J. A. (2007). The coding process and its challenges. In A. B. C. Charmaz (Ed.), *The SAGE handbook of grounded theory* (pp. 265-289). London: Sage.
- Holton, J. A., & Walsh, I. (2017). *Classic Grounded Theory: Applications with Qualitative & Quantitative Data*. Los Angeles: SAGE.
- Hui, D., & Bruera, E. (2016). Integrating palliative care into the trajectory of cancer care. *Nat Rev Clin Oncol*, 13(3), 159-171. doi:10.1038/nrclinonc.2015.201
- Hui, D., Meng, Y. C., Bruera, S., Geng, Y., Hutchins, R., Mori, M., . . . Bruera, E. (2016). Referral Criteria for Outpatient Palliative Cancer Care: A Systematic Review. *Oncologist*, 21(7), 895-901. doi:10.1634/theoncologist.2016-0006
- Johnston, B., Milligan, S., Foster, C., & Kearney, N. (2012). Self-care and end of life care-patients' and carers' experience a qualitative study utilising serial triangulated interviews. *Supportive Care in Cancer*, 20(8), 1619-1627. doi:10.1007/s00520-011-1252-3
- Jordhoy, M. S., Inger Ringdal, G., Helbostad, J. L., Oldervoll, L., Loge, J. H., & Kaasa, S. (2007). Assessing physical functioning: a systematic review of quality of life measures developed for use in palliative care. *Palliat Med*, 21(8), 673-682. doi:10.1177/0269216307083386
- Kaasa, S., & Loge, J. H. (2003). Quality of life in palliative care: principles and practice. *Palliat Med*, 17(1), 11-20. doi:10.1191/0269216303pm662ra
- Kaptchuk, T. J. (2001). The double-blind, randomized, placebo-controlled trial: Gold standard or golden calf? *Journal of Clinical Epidemiology*, 54(6), 541-549. doi:10.1016/s0895-4356(00)00347-4
- Laugsand, E. A., Kaasa, S., de Conno, F., Hanks, G., & Klepstad, P. (2009). Intensity and treatment of symptoms in 3,030 palliative care patients: a cross-sectional survey of the EAPC Research Network. *J Opioid Manag*, 5(1), 11-21.
- LeBlanc, T. W., Lodato, J. E., Currow, D. C., & Abernethy, A. P. (2013). Overcoming recruitment challenges in palliative care clinical trials. *J Oncol Pract*, 9(6), 277-282. doi:10.1200/jop.2013.000996
- Lethborg, C., Aranda, S., Bloch, S., & Kissane, D. (2006). The role of meaning in advanced cancer-integrating the constructs of assumptive world, sense of coherence and meaning-based coping. *J Psychosoc Oncol*, 24(1), 27-42. doi:10.1300/J077v24n01_03
- Lowe, S. S., Milligan, C., Watanabe, S. M., & Brearley, S. G. (2015). A Grounded Theory Approach to Physical Activity and Advanced Cancer: A Qualitative Study Protocol. *International Journal of Qualitative Methods*, 14, 10. doi:10.1177/1609406915617161
- Lowe, S. S., Watanabe, S. M., Baracos, V. E., & Courneya, K. S. (2009). Associations Between Physical Activity and Quality of Life in Cancer Patients Receiving Palliative Care: A

- Pilot Survey. *Journal of Pain and Symptom Management*, 38(5), 785-796.
doi:10.1016/j.jpainsymman.2009.03.006
- Lowe, S. S., Watanabe, S. M., Baracos, V. E., & Courneya, K. S. (2010). Physical activity interests and preferences in palliative cancer patients. *Support Care Cancer*, 18(11), 1469-1475. doi:10.1007/s00520-009-0770-8
- Lowe, S. S., Watanabe, S. M., Baracos, V. E., & Courneya, K. S. (2012). Determinants of physical activity in palliative cancer patients: an application of the theory of planned behavior. *J Support Oncol*, 10(1), 30-36. doi:10.1016/j.suponc.2011.07.005
- Lowe, S. S., Watanabe, S. M., Baracos, V. E., & Courneya, K. S. (2013). Home-based functional walking program for advanced cancer patients receiving palliative care: a case series. *Bmc Palliative Care*, 12, 9. doi:10.1186/1472-684x-12-22
- Lowe, S. S., Watanabe, S. M., & Courneya, K. S. (2009). Physical activity as a supportive care intervention in palliative cancer patients: a systematic review. *J Support Oncol*, 7(1), 27-34.
- Maddocks, M., & Wilcock, A. (2012). Exploring physical activity level in patients with thoracic cancer: implications for use as an outcome measure. *Supportive Care in Cancer*, 20(5), 1113-1116. doi:10.1007/s00520-012-1393-z
- Madill, A. (2008). Realism. In L. M. Given (Ed.), *The SAGE Encyclopedia of Qualitative Research Methods* (pp. 732-736). Thousand Oaks: Sage.
- Mak, M. H. J. (2002). ACCEPTING THE TIMING OF ONE'S DEATH: AN EXPERIENCE OF CHINESE HOSPICE PATIENTS. *Omega: Journal of Death & Dying*, 45(3), 245.
- Malcolm, L., Mein, G., Jones, A., Talbot-Rice, H., Maddocks, M., & Bristowe, K. (2016). Strength in numbers: patient experiences of group exercise within hospice palliative care. *Bmc Palliative Care*, 15, 8. doi:10.1186/s12904-016-0173-9
- Maxwell, J. A. (2012). *A realist approach for qualitative research*. Thousand Oaks: Sage.
- Maxwell, J. A., & Mittapalli, K. (2007). *The value of critical realism for qualitative research*. Paper presented at the Annual Conference of the International Association for Critical Realism, Philadelphia, PA.
- Mayor, S. (2017). Exercise and psychological interventions reduce cancer related fatigue, review finds. *Bmj*, 356, j1127. doi:10.1136/bmj.j1127
- McCarthy, M., Katz, S. D., Schipper, J., & Dickson, V. V. (2015). "I Just Can't Do It Anymore" Patterns of Physical Activity and Cardiac Rehabilitation in African Americans with Heart Failure: A Mixed Method Study. *Healthcare (Basel)*, 3(4), 973-986. doi:10.3390/healthcare3040973
- McKechnie, R., MacLeod, R., & Keeling, S. (2007). Facing uncertainty: the lived experience of palliative care. *Palliat Support Care*, 5(4), 367-376.
- McMillan, E. M., & Newhouse, I. J. (2011). Exercise is an effective treatment modality for reducing cancer-related fatigue and improving physical capacity in cancer patients and survivors: a meta-analysis. *Applied Physiology Nutrition and Metabolism-Physiologie Appliquee Nutrition Et Metabolisme*, 36(6), 892-903. doi:10.1139/h11-082
- Mishra, S. I., Scherer, R. W., Geigle, P. M., Berlanstein, D. R., Topaloglu, O., Gotay, C. C., & Snyder, C. (2012). Exercise interventions on health-related quality of life for cancer survivors. *Cochrane Database of Systematic Reviews*(8), 367. doi:10.1002/14651858.CD007566.pub2
- Mishra, S. I., Scherer, R. W., Snyder, C., Geigle, P. M., Berlanstein, D. R., & Topaloglu, O. (2012). Exercise interventions on health-related quality of life for people with cancer during active treatment. *Cochrane Database Syst Rev*, 8, Cd008465. doi:10.1002/14651858.CD008465.pub2
- Mustian, K. M., Alfano, C. M., Heckler, C., Kleckner, A. S., Kleckner, I. R., Leach, C. R., . . . Miller, S. M. (2017). Comparison of Pharmaceutical, Psychological, and Exercise

- Treatments for Cancer-Related Fatigue: A Meta-analysis. *JAMA Oncol.* doi:10.1001/jamaoncol.2016.6914
- NCCN. (2016). National Comprehensive Cancer Network (NCCN) Clinical practice guidelines in oncology: cancer-related fatigue. Retrieved from https://www.nccn.org/professionals/physician_gls/pdf/fatigue.pdf
- Nekolaichuk, C., Watanabe, S., & Beaumont, C. (2008). The Edmonton Symptom Assessment System: a 15-year retrospective review of validation studies (1991--2006). *Palliat Med*, 22(2), 111-122. doi:10.1177/0269216307087659
- O'Connor, M. K., Netting, F. E., & Thomas, M. L. (2008). Grounded theory: Managing the challenge for those facing Institutional Review Board oversight. *Qualitative Inquiry*, 14(1), 28-45.
- Olsson, L., Ostlund, G., Strang, P., Jeppsson Grassman, E., & Friedrichsen, M. (2010). Maintaining hope when close to death: insight from cancer patients in palliative home care. *Int J Palliat Nurs*, 16(12), 607-612. doi:10.12968/ijpn.2010.16.12.607
- Payne, S. (2007). Qualitative methods of data collection and analysis. In J. M. Addington-Hall, E. Bruera, I. J. Higginson, & S. Payne (Eds.), *Research Methods in Palliative Care* (pp. 139-161). Oxford: Oxford University Press.
- QELCCC. (2010). Quality End-of-Life Care Coalition of Canada Blueprint for Action 2010 to 2020. Retrieved from http://www.qelccc.ca/media/3749/eng_progress_report_20102012-07-10_2.pdf
- Radbruch, L., Strasser, F., Elsner, F., Goncalves, J. F., Loge, J., Kaasa, S., . . . Stone, P. (2008). Fatigue in palliative care patients -- an EAPC approach. *Palliat Med*, 22(1), 13-32. doi:10.1177/0269216307085183
- Reeve, J., Lloyd-Williams, M., Payne, S., & Dowrick, C. (2010). Revisiting biographical disruption: exploring individual embodied illness experience in people with terminal cancer. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine*, 14(2), 178-195 118p. doi:10.1177/1363459309353298
- Reid, J. (2009). Conducting qualitative research with advanced cancer patients and their families: ethical considerations. *Int J Palliat Nurs*, 15(1), 30-33. doi:10.12968/ijpn.2009.15.1.37950
- Reiner, M., Niermann, C., Jekauc, D., & Woll, A. (2013). Long-term health benefits of physical activity - a systematic review of longitudinal studies. *Bmc Public Health*, 13, 9. doi:10.1186/1471-2458-13-813
- Reyna, Y. Z., Bennett, M. I., & Bruera, E. (2007). Ethical and practical issues in designing and conducting clinical trials in palliative care. In J. Addington-Hall, E. Bruera, I. J. Higginson, & S. Payne (Eds.), *Research Methods in Palliative Care* (pp. 27-41). Oxford: Oxford University Press.
- Riley, S., Schouten, W., & Cahill, S. (2003). Exploring the dynamics of subjectivity and power between researcher and researched. *Forum: Qualitative Social Research*, 4(2).
- Rock, C. L., Doyle, C., Demark-Wahnefried, W., Meyerhardt, J., Courneya, K. S., Schwartz, A. L., . . . Gansler, T. (2012). Nutrition and physical activity guidelines for cancer survivors. *CA Cancer J Clin*, 62(4), 243-274. doi:10.3322/caac.21142
- Rodrigues, A. R., Trufelli, D. C., Fonseca, F., de Paula, L. C., & Giglio, A. D. (2016). Fatigue in Patients With Advanced Terminal Cancer Correlates With Inflammation, Poor Quality of Life and Sleep, and Anxiety/Depression. *Am J Hosp Palliat Care*, 33(10), 942-947. doi:10.1177/1049909115603055
- Ruijs, C. D., Kerkhof, A. J., van der Wal, G., & Onwuteaka-Philipsen, B. D. (2013). Symptoms, unbearable and the nature of suffering in terminal cancer patients dying at home: a prospective primary care study. *BMC Fam Pract*, 14, 201. doi:10.1186/1471-2296-14-201

- Ryan, Carroll, J. K., Ryan, E. P., Mustian, K. M., Fiscella, K., & Morrow, G. R. (2007). Mechanisms of cancer-related fatigue. *Oncologist*, 12 Suppl 1, 22-34. doi:10.1634/theoncologist.12-S1-22
- Ryan, A. B. (2006). Post-positivist approaches to research *Researching and Writing your thesis: a guide for postgraduate students* (pp. 12-26): MACE: Maynooth Adult and Community Education.
- Sackett, D. L., Rosenberg, W. M. C., Gray, J. A. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: What it is and what it isn't - It's about integrating individual clinical expertise and the best external evidence. *British Medical Journal*, 312(7023), 71-72.
- Schmiegelow, M., Feldt-Rasmussen, U., Rasmussen, A. K., Lange, M., Poulsen, H. S., & Muller, J. (2003). Assessment of the hypothalamo-pituitary-adrenal axis in patients treated with radiotherapy and chemotherapy for childhood brain tumor. *J Clin Endocrinol Metab*, 88(7), 3149-3154. doi:10.1210/jc.2002-021994
- Schmitz, K. H., Courneya, K. S., Matthews, C., Demark-Wahnefried, W., Galvao, D. A., Pinto, B. M., . . . Schwartz, A. L. (2010). American College of Sports Medicine roundtable on exercise guidelines for cancer survivors. *Med Sci Sports Exerc*, 42(7), 1409-1426. doi:10.1249/MSS.0b013e3181e0c112
- Seale, C. (1999). Trust, truth and philosophy. In C. Seale (Ed.), *The Quality of Qualitative Research* (pp. 19-32). London: Sage.
- Segal, R., Zwaal, C., Green, E., Tomasone, J. R., Loblaw, A., & Petrella, T. (2017). Exercise for people with cancer: a clinical practice guideline. *Curr Oncol*, 24(1), 40-46. doi:10.3747/co.24.3376
- Seow, H., Barbera, L., Sutradhar, R., Howell, D., Dudgeon, D., Atzema, C., . . . Earle, C. (2011). Trajectory of performance status and symptom scores for patients with cancer during the last six months of life. *J Clin Oncol*, 29(9), 1151-1158. doi:10.1200/jco.2010.30.7173
- Skipworth, R. J., Stene, G. B., Dahele, M., Hendry, P. O., Small, A. C., Blum, D., . . . Helbostad, J. L. (2011). Patient-focused endpoints in advanced cancer: criterion-based validation of accelerometer-based activity monitoring. *Clin Nutr*, 30(6), 812-821. doi:10.1016/j.clnu.2011.05.010
- Snape, D., & Spencer, L. (2003). The foundations of qualitative research. In J. Ritchie & J. Lewis (Eds.), *Qualitative Research Practice* (pp. 1-23). London: Sage.
- Speck, R. M., Courneya, K. S., Masse, L. C., Duval, S., & Schmitz, K. H. (2010). An update of controlled physical activity trials in cancer survivors: a systematic review and meta-analysis. *J Cancer Surviv*, 4(2), 87-100. doi:10.1007/s11764-009-0110-5
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Struck, B. D., & Ross, K. M. (2006). Health promotion in older adults. Prescribing exercise for the frail and home bound. *Geriatrics*, 61(5), 22-27.
- Teunissen, S. C., Wesker, W., Kruitwagen, C., de Haes, H. C., Voest, E. E., & de Graeff, A. (2007). Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manage*, 34(1), 94-104. doi:10.1016/j.jpainsymman.2006.10.015
- Torre, L. A., Bray, F., Siegel, R. L., Ferlay, J., Lortet-Tieulent, J., & Jemal, A. (2015). Global Cancer Statistics, 2012. *Ca-a Cancer Journal for Clinicians*, 65(2), 87-108. doi:10.3322/caac.21262
- Turner, K., Tookman, A., Bristowe, K., & Maddocks, M. (2016). 'I am actually doing something to keep well. That feels really good': Experiences of exercise within hospice care. *Progress in Palliative Care*, 24(4), 204-212. doi:10.1080/09699260.2015.1123441

- UN. (2015). World Population Ageing 2015. Retrieved from http://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf
- Van Lancker, A., Velghe, A., Van Hecke, A., Verbrugghe, M., Van Den Noortgate, N., Grypdonck, M., . . . Beeckman, D. (2014). Prevalence of symptoms in older cancer patients receiving palliative care: a systematic review and meta-analysis. *J Pain Symptom Manage*, 47(1), 90-104. doi:10.1016/j.jpainsymman.2013.02.016
- Walls, P., Parahoo, K., & Fleming, P. (2010). The role and place of knowledge and literature in grounded theory. *Nurse researcher*, 17(4), 8-17.
- Walsh, D., Donnelly, S., & Rybicki, L. (2000). The symptoms of advanced cancer: relationship to age, gender, and performance status in 1,000 patients. *Support Care Cancer*, 8(3), 175-179.
- Warburton, D. E. R., Charlesworth, S., Ivey, A., Nettlefold, L., & Bredin, S. S. D. (2010). A systematic review of the evidence for Canada's Physical Activity Guidelines for Adults. *International Journal of Behavioral Nutrition and Physical Activity*, 7, 220. doi:10.1186/1479-5868-7-39
- Watson, T., & Mock, V. (2004). Exercise as an intervention for cancer-related fatigue. *Phys Ther*, 84(8), 736-743.
- Welmer, A. K., Morck, A., & Dahlin-Lvanoff, S. (2012). Physical Activity in People Age 80 Years and Older as a Means of Counteracting Disability, Balanced in Relation to Frailty. *Journal of Aging and Physical Activity*, 20(3), 317-331.
- Wheeler, G. D. (1998). Challenging our assumptions in the biological area of adapted physical activity: A reaction to Shephard (1998). *Adapted Physical Activity Quarterly*, 15(3), 236-249.
- WHO. (2002). Active ageing: a policy framework. Retrieved from http://apps.who.int/iris/bitstream/10665/67215/1/WHO_NMH_NPH_02.8.pdf
- WHO. (2014). Global atlas of palliative care at the end of life. Retrieved from http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf
- WHO. (2015). WHO Definition of Palliative Care. Retrieved from <http://www.who.int/mediacentre/factsheets/fs402/en/>
- WHO. (2017). Cancer factsheet. Retrieved from <http://www.who.int/mediacentre/factsheets/fs297/en/>
- Willig, C. (2008a). From recipes to adventures *Introducing qualitative research in psychology: adventures in theory and method* (pp. 1-14). Maidenhead: McGraw Hill Open University Press.
- Willig, C. (2008b). Grounded Theory *Introducing qualitative research in psychology: adventures in theory and method* (2nd ed., pp. 34-51). Maidenhead: McGraw-Hill Open University Press.
- Willig, C. (2008c). Qualitative Research Design *Introducing Qualitative Research in Psychology: Adventures in Theory and Method* (pp. 15-33). Maidenhead: McGraw Hill / Open University Press.

Appendix A: Ethical Approval



28 October 2013

Dr. Kerry Courneya
Physical Education and Recreation
University of Alberta

Dear Dr. Courneya:

Re: 26163: An exploratory study of free-living activity and quality of life in advanced cancer patients

Thank you for submitting the proposal for the above named study. On behalf of the Alberta Cancer Research Ethics Committee (ACREC) I have reviewed the following documents as of 18 October 2013:

- Application for Research of Minimal Risk dated 07 October 2013 (received 11 October 2013)
- Main Consent Form dated 07 October 2013
- Protocol Version 1.0 dated 07 October 2013

Thank you also for your submission dated 23 October 2013 in response to ACREC correspondence dated 21 October 2013, together with the following:

- Revised Main Consent Form dated 23 October 2013

As of 28 October 2013, the following documents have been approved:

- Application for Research of Minimal Risk dated 07 October 2013 (received 11 October 2013)
- Main Consent Form dated 23 October 2013
- Protocol Version 1.0 dated 07 October 2013

Please note that this approval is based on the following conditions:

- if there are any other changes to the protocol during the year, a letter describing the changes must be forwarded to the ACREC;
- an Annual Renewal form must be submitted two months prior to the deadline date of **18 October 2014 (one year from the date of initial review)** containing the information as per our annual renewal form;
- a Final Report must be submitted at the termination of the project.

The deliberations of the ACREC include all elements described in Section 50 of the Health Information Act, and this study was found to be in compliance with all the applicable

Alberta Cancer Research Ethics Committee Suite 1400, Sun Life Place, 10123 -99 Street, Edmonton AB T5J 3H1
Tel: (780) 643-7123/ (780) 643-7135 Email: Research.Ethics@albertahealthservices.ca

1. The membership of this Research Ethics Committee complies with the membership requirements for Research Ethics Boards defined in Part C Division 5 of the *Food and Drug Regulations*;
2. This Research Ethics Committee carries out its functions in a manner consistent with Good Clinical Practices; and
3. This Research Ethics Committee has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted by the qualified investigator named above at the specified clinical trial site(s). This approval and the views of this Research Ethics Committee have been documented in writing.

requirements of the Act. The ACREC determined that consent will be obtained from study participants for disclosure of the health information to be used in the research.

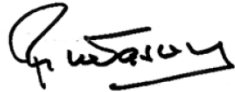
The Alberta Cancer Research Ethics Committee complies with the following guidelines and regulations:

- Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans;
- Health Information Act which has been proclaimed on April 25, 2001 in Alberta;
- Health Canada, as defined in C.05 (Part C Division 5) (1024 - Clinical Trials) of the Food And Drug Regulations -Amendment and the Therapeutic Products Directorate Guidelines /ICH Harmonized Tripartite Guidelines - Good Clinical Practice: Consolidate Guidelines;
- National Institutes of Health - Code of Federal Regulations (USA); and
- Our institution has been approved by the Office for Human Research Protections in the United States.

Members of the ACREC who are named as investigators or co/sub-investigators in research studies do not participate in discussion related to, nor vote on, such studies when they are presented to the ACREC.

Please accept the Committee's best wishes for success in your research.

Sincerely,



Raul Urtasun, M.D.
Associate Chair, Alberta Cancer Research Ethics Committee

/eg

cc: OIPC
Asifa Mawani
Clinical Research Unit – CCI
Caroline Shewchuk –CCI Pharmacy

Health Research Ethics Board

308 Campus Tower
University of Alberta, Edmonton, Alberta T6G 1K8
p.780.492.9724 (Biomedical Panel)
p.780.492.0302 (Health Panel)
p.780.492.0459
p.780.492.0039
t.780.492.7808

November 1, 2013

Dr. Kerry S. Courneya
Physical Education and Recreation
University of Alberta

Dear Dr. Courneya:

Re: ACREC File 26163: An Exploratory Study of Free-living Activity and Quality of Life in Advanced Cancer Patients

Thank you for submitting your ACREC application for reciprocal approval of the above noted study.

The Alberta Cancer Research Ethics Committee approved the Application for Research of Minimal Risk for the above named study on October 28, 2013.

This letter serves as the official acknowledgment that this ACREC approval has been accepted by the University of Alberta and by its Health Research Ethics Board. Please note that the ACREC will remain your REB-of-record and no further information related to this research will be required to be submitted to the University of Alberta, HREB.

Yours sincerely,



Lynn Penrod, PhD, LLM
Executive Director, Research Ethics Office
University of Alberta





Applicant: Sonya Lowe
Supervisors: Dr Sarah Brearley
Department: DHR

18 March 2014

Dear Sonya and Sarah,

Re: An exploratory study of free-living activity and quality of life in advanced cancer patients

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

S.C. Taylor

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, (Chair, UREC); Professor Paul Bates (Chair, FHMREC)

Research Support Office
Research and Enterprise Services

Lancaster University
Bowland Main
Lancaster LA1 4YT
United Kingdom

Tel: +44 (0) 1524 592002
Fax: +44 (0) 1524 593229
Web: <http://www.lancs.ac.uk>

Appendix B: Physician Request Letter

May 9, 2014

Dr. X

Medical Oncology

Cross Cancer Institute

Dear Dr. X,

RE: ACT10

ACB: #####

DOB: #####

My name is Sonya Lowe, and I am one of the palliative care research fellows at the Cross Cancer Institute. I am currently coordinating Alberta Cancer Board-approved research study ETH-26163: An exploratory study of free-living activity and quality of life in advanced cancer patients. The primary investigator is Dr. Kerry Courneya (tel: 492-1031).

The abovementioned patient expressed interest in participating in this research study. Study participants are asked to wear an *activPAL*™ activity monitor to record usual daily activity levels, and to fill out a daily record sheet, for one week. At the end of the week, a brief interview is conducted to elicit the participant's feelings, ideas and perceptions about usual daily activity in the context of what happened over the previous week. Eligibility criteria include the following: 1) patients 18 years of age or older 2) diagnosis of advanced cancer 3) palliative performance scale level of 30% or greater and 4) clinician-estimated prognosis of 12 months or less. There are no financial costs to the participants. If you would like further information about our study, please feel free to page me at (780) 445-5895.

I am writing to ask for your formal permission, as the treating oncologist, for this patient to participate in the study. If you could please sign this letter and fax (780-432-8419) it back to my attention, that would be greatly appreciated.

Sincerely,

Sonya Lowe, MD MSc

Alberta Cancer Foundation Roche Fellow in Translational Research

Pager: 780-445-5895

X_____

Signature of Dr. X for permission of abovementioned patient to participate in research study ETH-26163

Appendix C: Consent Form

An exploratory study of free-living activity and quality of life in advanced cancer patients

(A study to explore the usual daily activities and quality of life of patients with advanced cancer)

CONSENT FORM

This form is part of the process of informed consent. It is designed to explain this research study and what will happen to you if you choose to be in this study.

If you would like to know more about something mentioned in this consent form, or have any questions at anytime regarding this research study, please be sure to ask your doctor or nurse. Read this consent form carefully to make sure you understand all the information it provides. You will get a copy of this consent form to keep. You do not have to take part in this study and your care does not depend on whether or not you take part.

Your doctor has given us permission to ask you to be in this study.

Your participation in this study is entirely voluntary. Please take your time to make your decision. It is recommended that you discuss with your friends and/or family about whether to participate in this study.

"WHY IS THIS STUDY BEING DONE?"

You are being asked to take part in this study because you have advanced cancer.

Increasing evidence indicates a role for physical activity in improving quality of life outcomes in early stage cancer patients, including fatigue, physical functioning, mood and self-esteem. Research on physical activity and advanced cancer, however, is still very limited.

This study is being done because it is not known what the personal experience of usual daily activity is for patients with advanced cancer. No study has examined the meaning, perceptions, barriers and facilitators to free-living activity from the perspective of patients with advanced cancer.

"WHAT DO WE HOPE TO LEARN?"

The purpose of this study is to gain an in-depth understanding of the lived experience of free-living activity for patients with advanced cancer.

The specific objectives of the study are:

- 1. To explore the meaning of free-living activity for advanced cancer patients in the context of day-to-day life;**
- 2. To elicit advanced cancer patients' perceptions of free-living activity with respect to their quality of life; and**
- 3. To elicit advanced cancer patients' views of barriers and facilitators to free-living activity in the context of day-to-day life.**

"WHAT IS INVOLVED IN THIS STUDY?"

In this study, you will wear an activPAL™ activity monitor to record your usual daily activity levels, and fill out a daily record sheet, for one week. This will take place in your home or wherever your usual daily activities take you. At the end of the week, the researcher will collect the activity monitor, and ask you questions about your feelings, ideas and perceptions about usual daily activity in the context of what happened over the previous week. This interview will take place in your home or at the Cross Cancer Institute, at a time that is convenient for you.

"HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?"

About 30 people will take part in this study at the Cross Cancer Institute

"WHAT WILL MY PARTICIPATION INVOLVE?"

If you take part in this study, you will be asked to wear an activPAL™ activity monitor, which records movement in the form of lying, sitting,

quiet standing and stepping. The 20 gram, 35 x 53 x 7 millimetre unit is secured to your front mid-thigh using a sticky pad which you are asked to remove when bathing or showering, and replace once your underlying skin is dried. You are asked to wear the activPAL™ unit for one week. During that week, you will also be asked to fill out a daily record sheet asking you about your symptoms and general impressions of that day. This will take place in your home or wherever your usual daily activities take you.

At the end of the week, the researcher will share the activPAL™ activity monitor output with you, and ask you questions about your feelings, ideas and perceptions about free-living activity in the context of what happened over the previous week. This interview will take place in your home or at the Cross Cancer Institute, at a time that is convenient for you.

"HOW LONG WILL I BE INVOLVED IN THE STUDY?"

You may be in this study for as long as one week.

"WHAT ARE THE SIDE EFFECTS?"

There are no known risks associated with wearing the activPAL™ activity monitor.

During the study interview, it is possible that you may experience emotional distress upon recalling aspects of your cancer experience. If this is the case, please contact the investigators in charge of the study as listed on page 5 of this form. You may also contact the Department of Psychosocial and Spiritual Resources at (780) 643-4303 for further support.

"WHAT ARE THE REPRODUCTIVE RISKS?"

There are no known reproductive risks associated with this study.

"WHAT ARE MY RESPONSIBILITIES?"

You must be willing to attend all scheduled study visits and undergo all of the procedures described above. It is very important that you inform the investigator of any side effects or health problems that you may be

experiencing as well as any medications (prescribed or holistic) that you are taking while on this study.

"WHAT ARE MY ALTERNATIVES?"

You may choose not to participate in this study.

"ARE THERE ANY BENEFITS TO PARTICIPATING IN THIS STUDY?"

Participation in this study may or may not be of personal benefit to you. However, based on the results of this study, it is hoped that, in the long-term, patient care can be improved.

"CAN I WITHDRAW FROM THIS STUDY?"

In discussion with you, your doctor at the Cross Cancer Institute, either at their own initiative or at the request of the sponsor of this study, may withdraw you from the study at any time if it is in your best interests. Taking part in this study is voluntary; you may withdraw from the study at any time if you wish to do so. If you decide to stop participating in the study, we encourage you to talk to your doctor first.

Should you decide to withdraw from the study at any time, information collected on you up until that point would still be provided to the study investigator.

"ARE THERE COSTS TO ME FOR TAKING PART IN THIS STUDY?"

You will not have to pay for the treatment you receive in this study.

You may be coming to the Cross Cancer Institute more often than if you were not part of this study. There may be additional costs to you for taking part in this study such as:

- **Parking**
- **Transportation**

- **Meals**
- **Babysitting, etc.**

“WHAT ARE MY RIGHTS AS A PARTICIPANT?”

If you suffer an injury or become ill as a result of participating in this research, you will receive all medical treatments (or services) recommended by your doctors. No compensation will be provided beyond this point. However, it is important to note that nothing said in this consent form alters your legal rights to recover damages (e.g. legal action).

If new information becomes available or there are changes to the study that may affect your health or willingness to continue in the study, you will be told in a timely manner.

“WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?”

Identifiable health information will be collected from you and from your Provincial Electronic Health Record (NetCare) during this study. This information may be used by the researchers who are carrying out this study, and may be disclosed to others as described below. Any research proposal to use information that identifies you for a purpose other than this study must be approved in advance by the Alberta Cancer Research Ethics Committee.

Direct access to your identifiable health information collected for this study will be restricted to the researchers who are directly involved in this study except in the following circumstances:

Your identifiable health information may need to be inspected or copied from time to time for quality assurance (to make sure the information being used in the study is accurate) and for data analysis (to do statistical analysis that will not identify you). The following organizations may do this inspection:

- **Health Canada, the Canadian regulatory body**

- **Alberta Cancer Research Ethics Committee, the institutional review board at this centre**
- **Members of the Regulatory/Audit team at the Cross Cancer Institute for quality assurance purposes**

Any disclosure of your identifiable health information will be in accordance with the Alberta Health Information Act. As well, any person from the organizations listed above looking at your records on-site at the Cross Cancer Institute will follow the relevant Alberta Health Services - Alberta Cancer Research Ethics Committee policies and procedures that control these actions. Any disclosure of your identifiable health information to another individual or organization not listed here will need the approval of the Alberta Cancer Research Ethics Committee.

Your identifiable health information collected as part of this study which includes records of your progress, your responses to the questionnaires and your diaries will be kept confidential in a secure AHS facility. Information that does not identify you will also be provided to Alberta Health Services or other companies acting on behalf of Alberta Health Services, where it will be kept confidential in a secure location.

The researchers who are directly involved in your study may share information about you with other researchers, but you will not be identified in that shared information except by a number. The key that indicates what number you have been assigned will be kept secure by the researchers directly involved with your study and will not be released.

Although absolute confidentiality can never be guaranteed, Alberta Health Services will make every effort to keep your identifiable health information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information in accordance with the Alberta Health Information Act and other regulatory requirements.

The information collected during this study will be used in analyses and will be published and/or presented to the scientific community at meetings and in journals, but your identity will remain confidential. This information may also be used as part of a submission to regulatory authorities around the world to support the approval of the drug used in this research. It is expected that the study results will be published as soon as possible after completion. Your study doctor will be informed of the results of the study once they are known.

“WHO DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?”

For information about your disease and/or research related injury/illness, you may contact the Principal Investigator Dr. Kerry Courneya at (780) 492-2829, Co-Investigator Dr. Sonya Lowe at (780) 432-8318, or Research Nurse Asifa Mawani at (780) 432-8654, or page them through the Cross Cancer Institute Switchboard at (780) 432-8771 to answer any questions you have about this study.

If your doctor or study nurse has not been able to answer or resolve your questions and/or concerns about this study, or if you feel at any time that you have not been informed to your satisfaction about the risks, benefits, or alternatives to this study, or that you have been encouraged to continue in this study after you wanted to withdraw, you can call the Alberta Health Services Patient Relations Department toll free at 1-855-550-2555.

UNDERSTANDING OF PARTICIPANTS

I can refuse to take part or withdraw from this study at any time without jeopardizing my health care. If I continue to take part in the study, I will be kept informed of any important new developments and information learned after the time I gave my original consent.

I also give consent for the Principal Investigator and Alberta Health Services (the Custodian) to disclose identifiable health information, as per the Alberta Health Information Act, to the organizations mentioned on the previous pages.

I have read and understood all of the information in this consent form. I have asked questions, and received answers concerning areas I did not understand. I have had the opportunity to take this consent form home for review and discussion. My consent has not been forced or influenced in any way. I consent to participate in this research study. Upon signing this form I will receive a signed copy of the consent.

(PRINT NAMES CLEARLY)

Name of Patient

Signature of Patient

Date

**Name of Person Obtaining
Consent**

**Signature of Person
Obtaining Consent**

Date

Patient Study Number or Hospital Number: _____

Was the patient assisted during the consent process in one of the ways listed below?

☐ **Yes** ☐ **No**

If yes, please check the relevant box and complete the signature space below:

☐ **The consent form was read to the patient, and the person signing below attests that the study**

was accurately explained to, and apparently understood by the patient.

☐ **The person signing below acted as a translator for the patient during the consent process.**

Signature of person assisting

Date

In the consent discussion

Please note: More information regarding the assistance provided during the consent process should be noted in the medical record for the patient if applicable.

Appendix D: Daily Symptom Record Sheet

APPENDIX 1 – Daily Record Sheet

Wednesday May 21, 2014
How would you describe your day today?

Good ☐ Neutral ☐ Bad ☐

Please explain why: _____

Please circle the number that best describes:

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst possible pain

Not tired 0 1 2 3 4 5 6 7 8 9 10 Worst possible tiredness

Not nauseated 0 1 2 3 4 5 6 7 8 9 10 Worst possible nausea

Not depressed 0 1 2 3 4 5 6 7 8 9 10 Worst possible depression

Not anxious 0 1 2 3 4 5 6 7 8 9 10 Worst possible anxiety

Not dizzy 0 1 2 3 4 5 6 7 8 9 10 Worst possible dizziness

Best appetite 0 1 2 3 4 5 6 7 8 9 10 Worst possible appetite

Best feeling of wellbeing 0 1 2 3 4 5 6 7 8 9 10 Worst possible feeling of wellbeing

No shortness of breath 0 1 2 3 4 5 6 7 8 9 10 Worst possible shortness of breath

Other problem 0 1 2 3 4 5 6 7 8 9 10

Examples of Activities

01 - Walking

03 - Housework

(making meals, doing laundry, cleaning)

04 - Lawn & Garden

(picking flowers, watering lawn or garden)

05 - Lying

(resting, sleeping)

06 - Sitting

(reading, watching television)

07 - Self Care

(bathing, dressing, eating)

08 - Transportation

(riding in a car or bus, driving)

09 - Other

Rating of Perceived

Exertion (RPE)

0 Nothing at all

0.5 Very, very light

1 Very light

2 Light

3 Moderate

4 Somewhat hard

5 Hard

6

7 Very hard

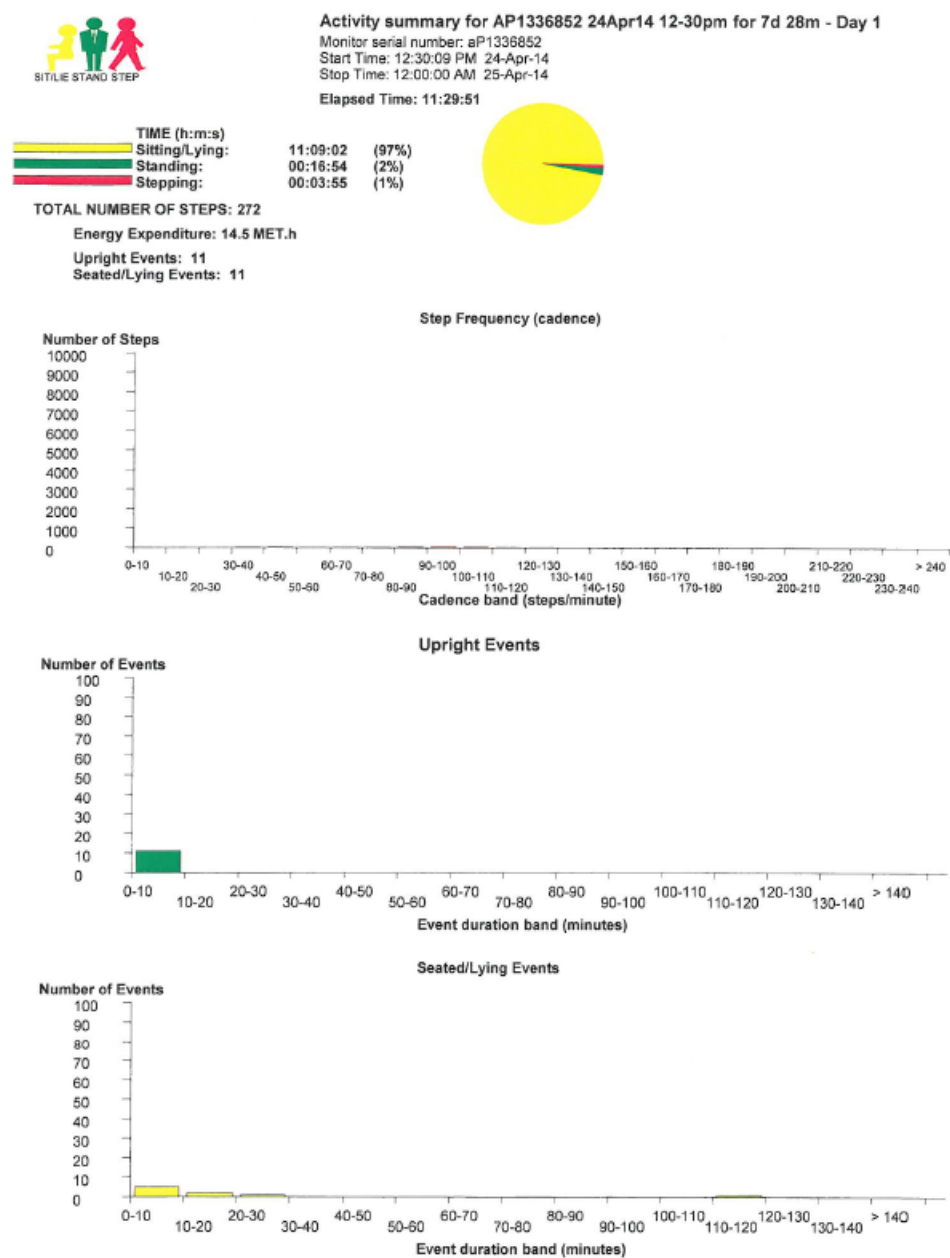
8

9

10 Very, very hard

Time of Day	Activity	Duration (minutes)	RPE (0-10)	Comments
Morning				
Afternoon				
Evening				

Appendix E: Sample Activity Monitor Output



PAL: Physical Activity Logging. © PAL Technologies Ltd 2001-2013



Activity profile for AP1336852 24Apr14 12-30pm for 7d 28m - Day 1

Monitor Serial Number: AP1336852
Start Time: 12:30 PM 24-Apr-14
Stop Time: 12:00 AM 25-Apr-14
Elapsed Time: 11:29

24-Apr-14 12 PM



Sit/Lie 26.8min
Stand 0.1min
Sleep 0.0min
0.0 steps
0.0 u/d transitions



EE (MET.h): 0.8



Sit/Lie 55.3min
Stand 1.1min
Sleep 0.3min
10 steps
0.2 u/d transitions



EE (MET.h): 1.3



Sit/Lie 55.5min
Stand 1.3min
Sleep 1.3min
20 steps
0.1 u/d transitions



EE (MET.h): 1.3



Sit/Lie 59.8min
Stand 0.0min
Sleep 0.0min
0 steps
0.0 u/d transitions



EE (MET.h): 1.2



Sit/Lie 59.8min
Stand 0.0min
Sleep 0.0min
0 steps
0.0 u/d transitions



EE (MET.h): 1.2



Sit/Lie 59.5min
Stand 0.1min
Sleep 0.1min
0 steps
0.0 u/d transitions



EE (MET.h): 1.3



Sit/Lie 58.0min
Stand 1.1min
Sleep 0.6min
14 steps
0.2 u/d transitions



EE (MET.h): 1.3



Sit/Lie 59.8min
Stand 0.0min
Sleep 0.0min
0 steps
0.0 u/d transitions



EE (MET.h): 1.2



Sit/Lie 59.8min
Stand 0.0min
Sleep 0.0min
0 steps
0.0 u/d transitions



EE (MET.h): 1.2



Sit/Lie 55.7min
Stand 1.2min
Sleep 0.6min
26 steps
0.2 u/d transitions



EE (MET.h): 1.3



Sit/Lie 54.0min
Stand 1.2min
Sleep 0.6min
28 steps
0.2 u/d transitions



EE (MET.h): 1.3



Sit/Lie 55.8min
Stand 0.0min
Sleep 0.0min
0 steps
0.0 u/d transitions



EE (MET.h): 1.2

Appendix F: Semi-structured Interview Guide

- The semi-structured interview will be guided by the *activPAL*™ activity monitor output and daily record sheets that the participant will have completed over the previous week
- The *activPAL*™ activity monitor output and daily record sheets will be different for each participant, and will therefore act as a unique interview probe for each participant
- The *activPAL*™ activity monitor output will be printed out and shared with the participant at the beginning of the interview, with subsequent interview questions informed by the patterns therein as well as the participant's reactions and observations
- Sample Questions (may vary depending on participant's activity monitor output and daily record sheets)
 - Please describe to me what happened on this day...
 - What else was happening that day when your activity was...
 - Are you surprised by what you see on the activity monitor output. Why or why not?
 - Why do you think your activity pattern is the way it is?
 - Would you like to engage in that activity more or less? Why or why not?
 - Are these usual daily activities important to you? If so, why?
 - Did your usual daily activities change with having cancer? If so, how?
 - What do your usual daily activities mean to you?
 - What would hinder you from engaging in your usual daily activities?
 - What helps you to engage in your usual daily activities?
 - What does quality of life mean to you?
 - Do you think your quality of life and your usual daily activities are related? If so, how?

Appendix G: Sample of Open Coding

S: Ok, so, ok, I've turned both of the recorders on, now.

ACT09: Is it OK if my daughter stays here?

S: Absolutely, absolutely, there's no trouble at all. Just going to put this aside, ok. So, ACT09, what I have here in front of you, is a printout from the activity monitor. So basically I will just first off, explain to you a little bit about what the information shows.

ACT09: Ok.

S: But I guess before we go into that, I wanted to ask you how you felt the week went?

ACT09: Um, basically without my other problems of my legs are so bad gaining fluid, and I was very down about that, because I could hardly lift them getting into the tub, but not, aside from that it was good. I had a lung drain on Monday, and another nurse came up this morning to do an abdomen drain, so that helps my breathing and my coughing, and generally I felt well except I was very concerned about my legs because I seem to be gaining weight and they just kept getting thicker and thicker, they've never been heavy up here, and the fluid has gone right up to the top now, and they took me off water pills because my blood pressure was low, but uh, [ACT09's home care nurse] phoned [ACT09's family physician] and I'm back on them, not quite as much but every second day because I really need them, they help me drop a few pounds, rather than gain like I've been doing, and they did help me go more often. So I'm glad I'm back on them again. And I just won't take my blood pressure tablet every day, it's only 1mg, and I take it as needed but I've been taking it almost regularly because I don't want my pressure to go high, but instead it's going too low. She takes my pressure laying down and then standing up and there's quite a difference sometimes, yeah. So that's aside from that, [researcher's name], I felt fairly well. But I was very depressed the last few days especially about my legs, and uh, aside from that – wellbeing, do you want a number? About 4 or 5 I guess, yeah. But this was a real, you know, problem.

S: Yes, it sounds like your legs are what you were most worried about.

ACT09: Oh, I was, I was, yeah. Even the coughing, shortness of breath, I've had that for a long time, and that always help when they do a drain,

they drain the tubes, so it wasn't too bad, but it was the legs that really got to me, and I was depressed about it, yeah.

Appendix H: List of Codes

Atlas.ti7 version 7.5.15

Project: Activity and Advanced Cancer Grounded Theory Study 041016

CODE LISTING (n=352)

1. Abdominal distension
2. Ability and quality of life
3. Ability to drive
4. Absence of falls
5. Accomplishment
6. Active treatment
7. Activity aggravating symptoms
8. Activity as way of life
9. Activity despite symptoms
10. Activity facilitators
11. Activity frequency
12. Activity improves sleep
13. Activity is not important to me
14. Activity location constraints
15. activity modification
16. Activity monitor positioning
17. activity norm
18. Activity purpose modification
19. Activity related to other's routine
20. Activity related to vocation
21. Activity time modification
22. Activity validation
23. Acupuncture
24. adjusting to new reality
25. Advance preparation
26. allowing for time and space
27. Anxiety / Rumination
28. Appetite
29. appreciation for what was taken for granted previously
30. Barriers to activity
31. basic activities of daily living

32. Bed exercises
33. Being accountable for one's actions
34. Belief in treatment effect
35. Belief that activity is good
36. Benefits outweigh risks
37. Biking
38. Breaking up routine
39. Brush with death
40. Building community
41. Building self-esteem
42. Cannot control others' actions
43. Changes in community
44. Climbing stairs
45. Community
46. Comparison with Other
47. Comparison with previous self
48. Complementary Medicine
49. Complementary Medicine trumps Western Medicine
50. Concern for loved ones
51. Constipation
52. Continuing mobility
53. Contribution
54. Cough
55. Cultural assimilation
56. Daily routine
57. Dancing
58. Day-to-day fluctuations
59. Dehydration
60. Delayed sequelae of activity
61. Delirium
62. Depression
63. Design improvement suggestions
64. Did I do a good job?
65. Dietary recommendations
66. Dietary sequelae
67. different ways of doing things
68. Difficulty with position transfers
69. Diplopia

70. Disease burden as lifting weights
71. Disliked activities
72. disregarding activity limitations
73. Disregarding professional advice
74. Divert focus / attention
75. Dizziness
76. Do your best with what you have
77. Doesn't feel like me
78. Doing activities independently
79. Doing your best in all that you do
80. don't be too hard on oneself
81. Driving
82. Driving assistance
83. Drowsiness
84. Dysphagia
85. Dyspnea
86. dyspnea support
87. Elevate extremities
88. Elevate HOB
89. Emotional Distress
90. Energy levels
91. Enjoying meals
92. Enjoying the outdoors solo
93. Enjoyment of travel
94. Enjoyment of work
95. Environment layout
96. Environmental destruction
97. Environmental impact
98. Environmental modifications
99. Eructation
100. Event aggravates symptoms
101. External motivation
102. Failed expectations
103. Faith
104. Family meaning of quality of life
105. Fatigue
106. Fear of aggravating symptoms
107. Feeling at home

108. Feeling defeated

109. Feeling included

110. Financial constraints

111. Focus on the positive

112. Frustration with family/friends

113. Frustration with health care team

114. Frustration with interviewer

115. Frustration with self

116. Fulfilled goals

117. Functioning

118. Gardening

119. GERD-like symptoms

120. Getting going on activity

121. Getting made / dressed up

122. Going outside of home environment

123. Going to the bathroom

124. Going to the gym

125. Good mobility

126. Gratitude

127. Happiness

128. Headaches

129. Health Professional knows best

130. Hearing impairment

131. Helps, but not sure how

132. Hiccough

133. High energy

134. High rating of perceived exertion

135. high symptoms = low activity

136. Hobbies

137. Holistic treatment

138. Home-based activity

139. home care support

140. Housework

141. I'm a survivor

142. Identity

143. Impact of symptom burden

144. Impaired balance

145. Impaired concentration

- 146. Improved Quality of Life
- 147. improved symptoms
- 148. Inability to do = lack of pride
- 149. inability to meet minimum of responsibility
- 150. Insomnia
- 151. Interacting with people
- 152. Irritant gag reflex
- 153. Keeping busy / occupied
- 154. Knee bends
- 155. Laundry
- 156. Learned experience
- 157. Lifting
- 158. Limiting activity
- 159. Living with uncertainty
- 160. Location of pain
- 161. Looking after oneself the best that one can
- 162. loss of independent way of life
- 163. loss of purpose
- 164. Loss of vocation
- 165. Low rating of perceived exertion
- 166. low symptoms = high activity
- 167. Maintaining relationships
- 168. Manual labour
- 169. Meal prep
- 170. Mechanical design critique
- 171. Medication for hypertension
- 172. Medication mis-management
- 173. Medication regime
- 174. Medication sequelae
- 175. Meditation
- 176. merely existing
- 177. Mind-body connection
- 178. Minimize bending
- 179. Minimum level of activity
- 180. Mobility supports
- 181. Moderate rating of perceived exertion
- 182. Monitor not worn
- 183. Motivation

184. Mourning leaving family behind

185. Moving / Unpacking

186. MOXA

187. Muscle cramps

188. muscle spasms

189. Muscle stretching

190. Napping

191. Nature of Pain

192. Nausea

193. Neuropathy

194. Night sweats

195. No dependents

196. No fear of falling

197. No longer dependents

198. No motivation to move

199. No quick fix

200. not being a burden on dependents

201. Not being active doesn't make me feel worse about myself

202. Not dwelling on the negative

203. not ready for next level of support

204. Nothing to Do

205. Only I know how to do it properly

206. Onset of symptoms

207. Open communication

208. Optimal time of day: afternoon

209. Optimal time of day: evening

210. Optimal time of day: just after patient awakens

211. Other's assessment of patient activity

212. Outdoor recreation

213. Outdoor recreation as part of living

214. Outdoor recreation supports

215. Pacing

216. Pain

217. Palliative abdominal paracentesis

218. Palliative pleurocentesis

219. palliative subcutaneous drainage

220. panic attacks

221. path of least resistance

222. Patient's sense of justice

223. Patient acceptance

224. Patient activity goals

225. Patient as carer

226. patient as child

227. patient as dependent

228. Patient as employee

229. Patient as entrepreneur

230. Patient as grandparent

231. Patient as leader

232. Patient as parent

233. Patient as student

234. Patient as trainer

235. Patient attitudes re: inactivity

236. Patient awareness of activity monitor

237. Patient awareness of limitations

238. Patient awareness of others

239. Patient decision-making

240. Patient dissatisfaction with activity level

241. Patient expectations of activity

242. Patient expectations of cure

243. Patient expectations of illness

244. Patient expectations of treatment

245. Patient experience of illness

246. Patient hopes going forward

247. Patient knows best

248. Patient meaning of activity

249. Patient meaning of quality of life

250. Patient project goals

251. Patient reaction to activity

252. Patient sedentary behaviour

253. Patient understanding of illness

254. Peer influence

255. Peripheral edema

256. Personal activity tracker

257. Physical disfigurement

258. Pleural effusion

259. Poor mobility

260. Poor quality of life

261. Poor recall of events

262. Poor sense of well-being

263. Poor symptoms

264. Position transfers

265. Previous experience with complementary medicine

266. Primary location of activity

267. Professional relationship

268. Purpose

269. Putting pressure on oneself

270. Qi Gong

271. Recreational activities

272. Reduce, reuse and recycle

273. Relaxation

274. Relief just knowing

275. relocation

276. Remedial work

277. Respecting limitations

278. Responsibility

279. restless legs

280. restlessness

281. Rigours / Chills

282. Safety Support

283. Self-assessment of activity level

284. Self-care

285. self-management of health

286. Self-management of medications

287. Sense of humour

288. Shifting priorities

289. Shopping

290. Sitting

291. Sitting position

292. Sitting supports

293. Sleep medication

294. Sleep supports

295. Sleeping location

296. Sleeping position

297. Slow speed of activity

298. Social inequity
299. Spending time with family / friends
300. Spousal grieving
301. Standing
302. Standing support
303. Staying in one position
304. stressful event
305. Stretched too thin
306. Struggle with holistic approach
307. support for illness experience
308. Support for instrumental activities of daily living
309. Support for patient's dependents
310. Support for patient projects
311. Support for position transfers
312. Symptom aggravators
313. Symptom alleviators
314. symptom control
315. Symptom intensity
316. Symptom inter-relationships
317. Syncope
318. Tai Chi
319. Takes longer to take effect
320. Taking it easy
321. taking personal space
322. taking pride in oneself
323. Taking pride in work
324. There's no urgency
325. Toileting
326. Tradition
327. Transfer of responsibility
328. Treadmill walking
329. Treatment sequelae
330. tree decorating
331. trial and error
332. Unable to maintain position
333. Urgent medical attention
334. Value in work
335. Visitors

336. Vocation and quality of life
337. Vocation modification
338. Voice change
339. Voluntary mobility
340. Volunteering
341. Walking
342. Walking / Taking the dog outside
343. Walking meditation
344. Walking supports
345. Weakness
346. Weather dependence
347. Western Medicine
348. what goes around comes around
349. Will to live
350. Working with one's hands
351. Yard maintenance
352. Yoga

Appendix I: List of Code Families

Atlas.ti7 version 7.5.15

Project: Activity and Advanced Cancer Grounded Theory Study 041016

CODE FAMILY LISTING (n=42)

1. Accomplishment
2. Activities
3. Activity barriers
4. Activity behaviour
5. Activity modifications for symptom control
6. Activity monitoring
7. Activity relations
8. BADLs
9. Changing functionality
10. Community
11. Complementary Medicine (single incident)
12. Contribution
13. Day-to-day routine
14. Disease and symptom treatment
15. Environmental modifications
16. Environmental stewardship
17. Feelings
18. Functional activity
19. IADLs
20. Identity
21. Keeping busy
22. Mobility
23. Outdoor recreation
24. Patient beliefs
25. Patient expectations

26. Patient experience
27. Patient roles
28. Physical burden
29. Positioning
30. Provision for self
31. Quality of life
32. Recreational activity
33. Relationships
34. Respect for limitations
35. Responsibility
36. Sedentary behaviour
37. Self-sufficiency
38. Supports
39. Symptom relations
40. Symptoms
41. Understanding of illness
42. Vocation relations

Appendix J: List of Memos

1. "every little bit counts" (Interview ACT14)
2. "Speeding up to slow down" (Minimum level of activity: Interview ACT14)
3. Absence of the "sick role" (Interview ACT03, ACT05)
4. Acceptance of declining activity levels (Interviews ACT02, ACT07)
5. Accomplishment (There's no urgency: Interview ACT02; Taking pride in oneself: Interviews ACT02, ACT04, ACT15; Working with one's hands: Interviews ACT02, ACT05-06; Taking pride in work: Interviews ACT02, ACT05-06, ACT09, ACT11-13, ACT15; Accomplishment: Interviews ACT03, ACT06-07, ACT11, ACT14-15; Inability to do = lack of pride: Interviews ACT02-03, ACT06)
6. Accountability (Interviews ACT02, ACT05; Being accountable for one's actions: ACT05; Patient awareness of others: Interview ACT05; Social inequity: Interview ACT02; Patient's sense of justice: Interview ACT05; Cannot control another's actions: Interview ACT05)
7. Activities (Tree decorating: Interviews ACT11, ACT13; Moving/unpacking: Interview ACT11; Walking/taking the dog outside: Interviews ACT07, ACT10, ACT13; Relocation: Interviews ACT11, ACT15; Volunteering: Interview ACT15)
8. Activity as Accomplishment
9. Activity as being part of life (Activity as way of life: Interviews ACT02-03, ACT08, ACT11-13, ACT15)
10. Activity as purpose (Interview ACT02)
11. Activity behaviour (Walking: Interviews ACT01-02, ACT05-13, ACT15; Standing: Interviews ACT08-11, ACT15)
12. Activity is not important to me (Activity is not important to me: Interviews ACT07, ACT12)
13. Activity modification for symptom control (Staying in one position: Interview ACT08; Continuing mobility: Interviews ACT02, ACT15; Interviews ACT03-06, ACT08-12, ACT15; ACT02-04, ACT08-09; Minimizing bending: Interview ACT07; Fear of aggravating symptoms: Interviews ACT10, ACT13; Pacing: Interviews

ACT03-06, ACT08-12, ACT15; Activity modification: Interviews ACT09-11, ACT15; Taking it easy: Interviews ACT02, ACT04-05, ACT08-09, ACT11; Limiting activity: Interviews ACT03, ACT08-09)

14. Activity monitoring (Monitor not worn: Interviews ACT08-10; Personal activity tracker: Interview ACT12; Activity monitor positioning: Interviews ACT08-15; Patient awareness of activity monitor: Interviews ACT01-06, ACT09-10, ACT12, ACT14; Activity validation: Interviews ACT03-15;

15. Activity relations (Activity location constraints: Interview ACT15; Activity purpose modification: Interview ACT15; Activity improves sleep: Interview ACT02; Activity norm: Interview ACT12; Outdoor recreation as part of living: Interview ACT02; Dislike activities: Interview ACT05; Patient dissatisfaction with activity level: Interview ACT03; Relaxation: Interview ACT15; Other's assessment of patient activity: Interviews ACT10-11; Activity frequency: Interviews ACT11, ACT12, ACT15; Primary location of activity: Interviews ACT02, ACT15; Activity facilitators: Interviews ACT04, ACT10, ACT12-14; Slow speed of activity: Interviews ACT08-09, ACT11-12, ACT15; Home-based activity: Interviews ACT08, ACT10-15; Patient reaction to activity: Interviews ACT01-02, ACT05-11, ACT12, ACT14-15; Barriers to activity: Interviews ACT07-15; Delayed sequelae of activity: Interviews ACT03, ACT05-06, ACT12-13; Getting going on activity: Interviews ACT06, ACT09, ACT15; Activity time modification: Interviews ACT02, ACT04-14; Different ways of doing things: Interview ACT09; Activity aggravating symptoms: Interviews ACT02-15; Advance preparation: Interviews ACT09, ACT13; Disregarding activity limitations: Interviews ACT03-04, ACT07; Activity related to others' routine: Interviews ACT04-05, ACT07-09, ACT11-12; Activity despite symptoms: Interviews ACT10-13; Interviews ACT03-04, ACT07, ACT13; ACT10-13)

16. Adapting to Physical Decline: ACT15 (Interview ACT15)

17. Anhedonia

18. Assistance (Interviews ACT09, ACT15)

19. Barriers to activity

20. Basic activities of daily living (Position transfers: Interviews ACT02, ACT04-11; Basic activities of daily living: Interview ACT09, ACT13; Getting made/dressed up: Interview ACT09)
21. Being one's own boss: the entrepreneur (Interview ACT14)
22. Career and purpose (Interview ACT10)
23. Caregiver versus being cared for (Interviews ACT04, ACT07)
24. Caregiving (Interviews ACT04, ACT06-07, ACT09-15)
25. Caregiving pets (Interviews ACT07, ACT10)
26. Caring for the home environment
27. Changing functionality (Functioning: Interviews ACT01-04, ACT06-10, ACT15; Motivation: Interviews ACT02, ACT10-11, ACT13; Poor mobility: Interviews ACT01, ACT04, ACT06, ACT08, ACT14-15; Adjusting to new reality: Interview ACT14)
28. Community (Building community: Interviews ACT02, ACT15; Interviews ACT02, ACT04, ACT15)
29. Comparative Analysis: A15 versus A11 (Interviews ACT15, ACT11)
30. Comparative Analysis: ACT01 versus ACT14 (Interviews ACT01, ACT14)
31. Comparative analysis: ACT02 versus ACT07 (Interviews ACT02, ACT07)
32. Comparative Analysis: ACT12 versus ACT10 (Interviews ACT12, ACT10)
33. Complementary Medicine
34. Contribution (what goes around comes around: Interview ACT15; Interviews ACT02-03, ACT06, ACT08-11, ACT13, ACT15)
35. Critical Role versus Responsibility (Interviews ACT05, ACT07-08, ACT11)
36. Critical threshold of responsibility (Interviews ACT04-06, ACT08-10, ACT11-15)
37. Day-to-day fluctuations (Interviews ACT01-03, ACT05-06, ACT08-10, ACT15)
38. Day-to-day routines (Daily routine: Interviews ACT04-15)
39. Defining the critical role (Interviews ACT05, ACT11, ACT14-15)

40. Delegating versus Transferring Responsibility (Transfer of responsibility: Interviews ACT09, ACT11-12, ACT14-15; Interviews ACT04, ACT09, ACT11-12, ACT15)
41. Delegating: ACT04 (Interview ACT04)
42. Determination of responsibility: ACT02 (Interview ACT02)
43. Deviations from classic GT
44. Different levels within the home environment (Interviews ACT07, ACT09, ACT11, ACT12)
45. Dignity and Contribution (Interview ACT06)
46. Disease and Symptom Treatment (Interviews ACT01, ACT03, ACT08-11; ACT09; Urgent medical attention: Interviews ACT10, ACT14; Palliative abdominal paracentesis: Interview ACT09; Palliative pleurocentesis: Interview ACT09; Health professional knows best: Interviews ACT01-04, ACT06, ACT09-11, ACT13-15; Disregarding professional advice: Interview ACT04; Patient decision-making: Interview ACT01; Dietary sequelae: Interviews ACT01, ACT06; Medication regime: Interviews ACT01, ACT03-07, ACT09-14; Active treatment: Interviews ACT08-10, ACT12, ACT15; Benefits outweigh risks: Interview ACT09; Patient decision-making: Interview ACT01; Treatment sequelae: Interview ACT01, ACT03, ACT08-11)
47. Distillation | ACT01 (Interview ACT01)
48. Downsizing (Interviews ACT03-06, ACT08-10, ACT11-15)
49. Driving (Ability to Drive: Interviews ACT01, ACT04-05, ACT10, ACT15; Driving: Interviews ACT02-03, ACT05, ACT10-11; Driving assistance: Interviews ACT01, ACT03-04, ACT08-12, ACT14-15)
50. Duty versus Personal Feelings (Interviews ACT02-15)
51. Elderly parent (Interviews ACT11, ACT13)
52. Environmental modifications (Environmental layout: Interviews ACT01, ACT03-05, ACT08-15; Interviews ACT01, ACT03-05, ACT08-15)
53. Environmental stewardship: ACT02 (Interview ACT02)
54. Equipment mobility supports: ACT14 (Interviews ACT09-10, ACT 13-14)
55. External motivation: ACT12 (Interview ACT12)

56. Facing consequences of one's actions
57. Feelings (Frustration with health care team: Interviews ACT06, ACT09, ACT10-11; Interviews ACT02-03, ACT06, ACT09-10, ACT13)
58. Functional activity (Climbing stairs: Interviews ACT01, ACT05, ACT07-14; Lifting: Interview ACT11; Knee bends: Interview ACT06; Muscle stretching: Interview ACT15; Bed exercises: Interview ACT06)
59. Future Research Ideas
60. Gender and Contribution (Interviews ACT05, ACT10, ACT13, ACT15)
61. Getting in sync with one's body
62. Glaser's comment (Interview ACT14)
63. Goals (Patient project goals: Interviews ACT02-03, ACT05-06, ACT08-11, ACT14-15; Fulfilled goals: Interviews ACT02-03, ACT06, ACT09, ACT11, ACT15; Interviews ACT01-03, ACT05, ACT09-15)
64. Going Out (Going outside of home environment: Interviews ACT03-05, ACT07-15)
65. High Symptom Burden (Interviews ACT01-15)
66. How goal setting changes at the end of life (Interviews ACT07, ACT10, ACT12)
67. I am not defined by my limitations (Interviews ACT06, ACT11)
68. Instrumental activities of daily living (Interviews ACT01-06, ACT08-15; Yard maintenance: Interviews ACT02, ACT08, ACT13; Shopping: Interviews ACT09-15; Housework: Interviews ACT05, ACT08-15; Meal prep: Interviews ACT05-06, ACT08-12, ACT14-15)
69. Integrating the Whole: ACT15 (Interview ACT15)
70. Intention to Action transition
71. Internal motivation (Interviews ACT09, ACT13)
72. Intervention Planning
73. Just being
74. Keep living: ACT13 (Interview ACT13)
75. Keeping busy

76. Lack of purpose (Interview ACT03, ACT05, ACT10)
77. Lack of recreational activity
78. Lack of sleep
79. Leadership role (Interviews ACT02, ACT13-15)
80. Length of time participant has had this responsibility (Interviews ACT05, ACT10, ACT15)
81. Letting others help (Interviews ACT08, ACT10, ACT15)
82. Limitations (Interviews ACT01-07, ACT09)
83. Link to ACT11 (Interview ACT11)
84. Lit Rev Elliott - Hope as a Verb
85. Lit Rev Elliott - Key Relations
86. Lit Rev Goldsteen - Key Relations
87. Lit Rev Goldsteen - Living one's life till the end
88. Lit Rev Goldsteen - Normative Expectations
89. Lit Rev Goldsteen - Understanding of illness
90. Lit Rev Ho - Future Planning
91. Lit Rev Ho - Identity
92. Lit Rev Ho - Key Relations
93. Lit Rev Ho - Locus of Control
94. Lit Rev Ho - Maintaining Dignity
95. Lit Rev Ho - Person Supports
96. Lit Rev Ho - Purpose / Contribution
97. Lit Rev Ho - Self-sufficiency
98. Lit Rev Ho - Understanding of Illness
99. Lit Rev Johnston - Activities of Daily Living
100. Lit Rev Johnston - Disease and Symptom Treatment Strategies
101. Lit Rev Johnston - Environment Layout
102. Lit Rev Johnston - Equipment Supports
103. Lit Rev Johnston - Locus of Control
104. Lit Rev Johnston - Path of Least Resistance

- 105. Lit Rev Johnston - Person Support
- 106. Lit Rev Johnston - Preparing for Death
- 107. Lit Rev Johnston - Purpose / Contribution
- 108. Lit Rev Johnston - Self-Care
- 109. Lit Rev Johnston - Understanding of Illness
- 110. Lit Rev Lethborg - Acute Stressors
- 111. Lit Rev Lethborg - Day-to-day fluctuations
- 112. Lit Rev Lethborg - Key Relations
- 113. Lit Rev Lethborg - Person Supports
- 114. Lit Rev Lethborg - Priorities
- 115. Lit Rev Lethborg - Purpose / Contribution
- 116. Lit Rev Mak - Accomplishment
- 117. Lit Rev Mak - Key Relations
- 118. Lit Rev Mak - Meaning and Responsibility
- 119. Lit Rev McKechnie - Critical Threshold
- 120. Lit Rev McKechnie - Day-to-day fluctuations
- 121. Lit Rev McKechnie - Disease Burden
- 122. Lit Rev McKechnie - Downsizing
- 123. Lit Rev McKechnie - Key Relations
- 124. Lit Rev McKechnie - Person Support
- 125. Lit Rev McKechnie - Relinquishing Control
- 126. Lit Rev McKechnie - Symptom Burden
- 127. Lit Rev McKechnie - Transferring Responsibility
- 128. Lit Rev Olsson - Comparative Analysis with Reeve
- 129. Lit Rev Olsson - Comparative Analysis with Ruijs
- 130. Lit Rev Olsson - Contribution
- 131. Lit Rev Olsson - Day-to-day routine
- 132. Lit Rev Olsson - Key Relations
- 133. Lit Rev Olsson - Personal Responsibility
- 134. Lit Rev Olsson - Self-Management of Health

135. Lit Rev Reeve - Acute Stressors
136. Lit Rev Reeve - Comparative Analysis with Ruijs
137. Lit Rev Reeve - Day-to-Day Routine
138. Lit Rev Reeve - Disease as Embodied Burden
139. Lit Rev Reeve - Energy Restoration versus Conservation
140. Lit Rev Reeve - Meaning and Identity is NOT the driver
141. Lit Rev Reeve - Person Support
142. Lit Rev Ruijs - Ability to do
143. Lit Rev Ruijs - Activities of Daily Living
144. Lit Rev Ruijs - Meaning and Autonomy
145. Lit Rev Ruijs - physical functioning
146. Lit Rev Ruijs - Symptom burden
147. living arrangement decisions
148. Loss of control (Interviews ACT06, ACT09-10, ACT13-15)
149. Maintaining sense of balance
150. Meaning versus Purpose (Interviews ACT03, ACT05, ACT09-12, ACT15)
151. Medication relations (Medication sequelae: Interviews ACT01, ACT04-05, ACT09-11, ACT13-15; Medication regime: Interviews ACT01, ACT03-07, ACT09-14)
152. Meditation
153. Mentoring and Responsibility: ACT02 (Interview ACT02, ACT15)
154. Mind-body connection and wellness (Interviews ACT13, ACT15)
155. Mobility (Safety support: Interview ACT13; Mobility supports: Interviews ACT01, ACT04, ACT06-11, ACT13-15; Voluntary mobility: Interviews ACT02-03, ACT06, ACT11-12, ACT15; Good mobility: Interviews ACT01, ACT05-06, ACT10, ACT13, ACT15; Walking supports: Interview ACT06)
156. Must Do Tasks (Interview ACT04)
157. Nature of the caregiving relationship (Interviews ACT02, ACT07, ACT10-11, ACT15)
158. Nicknames

159. Not meeting personal expectations (Failed expectations: Interviews ACT03-04, ACT06-10, ACT12-15)
160. Not meeting responsibility: ACT03 (Interview ACT03)
161. Nothing to Do: ACT14 (Interview ACT05, ACT14)
162. Open Communication: ACT11 (Interview ACT11)
163. Outdoor recreation
164. Overall health and wellbeing: ACT15 (Interview ACT15)
165. Overcoming Physical Limitations: ACT11 (Interview ACT11)
166. Pain (Interviews ACT01-15; Nature of Pain: Interviews ACT01, ACT05-09, ACT13-14; Neuropathy: Interviews ACT02, ACT08, ACT10, ACT11; Location of pain: Interviews ACT01-05, ACT07-15)
167. Parenting role (Not being a burden on dependents: Interviews ACT08-09, ACT11; Patient as dependent: Interviews ACT09, ACT15; No longer dependent: Interviews ACT08 and ACT15; Patient as parent: Interviews ACT02, ACT06, ACT09, ACT11, ACT13-15)
168. Passing onto children: ACT15 (Interview ACT15)
169. Patient as child (Interviews ACT09-11, ACT13)
170. Patient as employee (Interviews ACT05, ACT08, ACT12, ACT13)
171. Patient as grandparent: ACT11 (Interview ACT11)
172. Patient as teacher (Interviews ACT02, ACT06, ACT13, ACT15)
173. Patient awareness of limitations (Interviews ACT02-10, ACT13-15)
174. Patient beliefs (Interview ACT09; Interviews ACT01-13, ACT09-10)
175. Patient expectations (Patient expectations of activity: Interviews ACT01-06, ACT08, ACT12, ACT15; Patient expectations of illness: Interviews ACT02-07, ACT09-12, ACT15)
176. Patient experience (Allowing for time and space: Interview ACT11; Stressful event: Interviews ACT10-11, ACT15; Shifting priorities: Interviews ACT11, ACT15; Learned experience: Interviews ACT05, ACT11; Allowing for time and space, Taking personal space: ACT11)

177. Perceived exertion (Low rating of perceived exertion: Interviews ACT08-09, ACT11-14; Moderate rating of perceived exertion: Interviews ACT09, ACT11-14)
178. Personal relationships (Mourning leaving family behind: Interview ACT11; Concern for loved ones: Interviews ACT05, ACT09, ACT11; Maintaining relationships: Interviews ACT02-03, ACT11, ACT15; Spending time with family/friends: Interviews ACT02-15)
179. Physical Burden (Disease burden as lifting weights: Interviews ACT05, ACT09, ACT11; Physical disfigurement: Interview ACT06;
180. Planning for the future without me in it (Interviews ACT06, ACT11, ACT14-15)
181. Positioning of activities (Unable to maintain position: Interviews ACT06, ACT09-10; Interviews ACT01, ACT06-11, ACT14)
182. Pride in what you are able to do (Interview ACT02)
183. Prioritization (Interviews ACT03-06, ACT08-10, ACT11-15)
184. Provision for self at end of life (Interviews ACT01-15)
185. Purpose (Interviews ACT02-03, ACT05, ACT09-10)
186. Purpose and Vocation (Interviews ACT05, ACT10)
187. Re-defining contribution (Interview ACT05)
188. Recreational Activities (Treadmill walking: Interview ACT12; Dancing, Biking: Interview ACT09; Yoga: Interviews ACT13, ACT15; Going to the gym: Interviews ACT07, ACT10; Recreational activities: Interviews ACT02-03; Gardening: Interview ACT09; Hobbies: Interviews ACT05-07, ACT09-10)
189. Recreational activity is primarily in the past
190. Reduce, reuse and recycle
191. Reframing the Meaning of Activity (Patient meaning of activity: Interviews ACT08-10, ACT13-15)
192. Regaining sense of normality: ACT12 (Interview ACT12)
193. Research Diary
194. Resignation | ACT01 (Interview ACT01)

195. Respect for Limitations (Do your best with what you have: Interviews ACT02, ACT04, ACT06-07, ACT09, ACT14-15; Interviews ACT02-06, ACT08-15)
196. Responsibility (inability to meet minimum of responsibility: Interviews ACT03, ACT10, ACT14; Interviews ACT04-06, ACT08-09, ACT11-15)
197. Responsibility and burden (Interviews ACT02-06, ACT09-10, ACT11, ACT13-15)
198. Responsibility and Identity (Interviews ACT02-06, ACT09-10, ACT11-15)
199. Responsibility as "life code" (Interview ACT14)
200. Responsibility for self: ACT15 (Interview ACT15)
201. Role as caregiver (Patient as carer: Interviews ACT04, ACT06-07, ACT09-15; Interviews ACT04, ACT06-07, ACT09-15)
202. Role as trainer (Interview ACT02)
203. Sedentary Behaviour (Not being active doesn't make me feel worse about myself: Interview ACT07; Patient sedentary behaviour: Interviews ACT01, ACT03-11, ACT13; No motivation to move: Interviews ACT06, ACT08-10; Path of least resistance: Interview ACT10)
204. Seeking validation (Interviews ACT03, ACT09)
205. Selection Bias
206. Self-assessment of activity level
207. Self-care: the core responsibility (Interviews ACT03-06, ACT08-10, ACT13-14)
208. Self-Concept (Interviews ACT02, ACT10, ACT15)
209. Self-Health as the primary responsibility (Self-management of health: Interviews ACT03, ACT06, ACT09; Interviews ACT01, ACT03-04, ACT09-11)
210. Self-sufficiency (Loss of independent way of life: Interviews ACT08, ACT10-11; Doing activities independently: Interviews ACT03, ACT08-11, ACT14-15)
211. Sliding scale of responsibility (Interviews ACT03-06, ACT08-10, ACT11-15)
212. Social inequity
213. Student role (Interviews ACT10, ACT12)

214. Support for BADLs (Safety support: Interview ACT13; Support for position transfers: Interviews ACT02-03, ACT06, ACT09-11, ACT14)
215. Supports (Not ready for next level of support: Interview ACT09; Support for illness experience: Interviews ACT09-11; Support for IADLs: Interviews ACT02-04, ACT06, ACT08-15; Home care supports: ACT05-06, ACT09)
216. Symptom control trumps all (Interviews ACT04-05, ACT07-15)
217. Symptom Relations (Dyspnea support: Interview ACT08; Onset of symptoms: Interviews ACT09-15; Poor symptoms: Interviews ACT01, ACT03-15; Symptom inter-relationships: Interviews ACT08, ACT13; Symptom intensity: Interviews ACT08-10; Interview ACT13; Interviews ACT08-10, ACT13; Symptom aggravators: Interviews ACT02, ACT04-06, ACT08-09, ACT13-15; High rating of perceived exertion: Interviews ACT08-12)
218. Symptoms (Drowsiness: Interviews ACT08-10; Energy levels: Interviews ACT01, ACT06; Impaired concentration: Interviews ACT03, ACT08, ACT10; Weakness: Interviews ACT01-02, ACT10, ACT14-15; Fatigue: Interviews ACT01-13, ACT15; Interviews ACT01-15; Dyspnea: Interviews ACT03, ACT06-09, ACT11-13)
219. Syncope
220. Taking on more responsibility (Interview ACT10)
221. Taking pride in vocation as parent (Interviews ACT02, ACT15)
222. The effects of chemotherapy: ACT08 (Interview ACT08)
223. The effects of paracentesis
224. The effects of radiotherapy: ACT01 (Interview ACT01)
225. The importance of activity
226. Then versus Now
227. Tradition (Interviews ACT02, ACT09, ACT11, ACT15)
228. Training for life
229. Treadmill walking
230. Understanding of illness (Patient acceptance: Interviews ACT01-03, ACT05-07, ACT09, ACT11; Interviews ACT01-03, ACT05-07, ACT09, ACT11)

231. Vocation relations (Vocation modification: Interviews ACT08, ACT12, ACT15; Activity related to vocation: Interviews ACT02, ACT04-05, ACT08-10, ACT12-13; Loss of vocation: Interviews ACT05, ACT10-13; Value in work / Manual labour: Interview ACT02; Vocation and quality of life: Interviews ACT02, ACT05, ACT13, ACT15)
232. Walking the dog
233. What determines critical to-do- list (Interviews ACT02-06, ACT08-11, ACT13-15)
234. What is healthy?: ACT15 (Interview ACT15)
235. What is quality of life (Ability and quality of life: Interviews ACT02-14; Interviews ACT01, ACT03-04, ACT06, ACT08-10, ACT14)
236. When inactivity is not accomplishment
237. Work / School adaptations
238. Work is no longer the priority (Interviews ACT08, ACT15)

Appendix K: Sample Search Strategies for Web of Science, PsycINFO, Academic Search Complete, and CINAHL

Search History – Web of Science

Set	
#13	#12 AND #11 <i>DocType=All document types; Language=All languages;</i>
#12	TOPIC: (questionnaire OR survey OR interview OR focus group OR case stud* OR observ* OR grounded theory OR narrative OR thematic OR experienc* OR content analysis OR ethnolog OR qualitative OR quantitative OR mixed methods) <i>DocType=All document types; Language=All languages;</i>
#11	#10 AND #7 <i>DocType=All document types; Language=All languages;</i>
#10	#9 OR #8 <i>DocType=All document types; Language=All languages;</i>
#9	TOPIC: (responsibility OR duty OR accountability OR obligation) <i>DocType=All document types; Language=All languages;</i>
#8	TOPIC: (personal autonomy OR paternalism OR self concept OR choice behavior OR decision making OR patient participation OR refusal to participate OR sick role) <i>DocType=All document types; Language=All languages;</i>
#7	#6 AND #5 <i>DocType=All document types; Language=All languages;</i>
#6	#4 OR #3 <i>DocType=All document types; Language=All languages;</i>
#5	#2 OR #1 <i>DocType=All document types; Language=All languages;</i>
#4	TOPIC: (end of life OR end-of-life OR end-stage OR "end stage" OR "terminal cancer" OR "advanced cancer" OR dying OR palliative OR hospice) <i>DocType=All document types; Language=All languages;</i>
#3	TOPIC: (palliative care OR palliative medicine OR terminal care OR hospice care) <i>DocType=All document types; Language=All languages;</i>
#2	TOPIC: (cancer) <i>DocType=All document types; Language=All languages;</i>
#1	TOPIC: (neoplasms) <i>DocType=All document types; Language=All languages;</i>

Search History – PsycINFO

Set	
1.	neoplasms.mp. or exp NEOPLASMS/
2.	cancer.mp. or exp Neoplasms/
3.	(palliative care or palliative medicine or terminal care or hospice care).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
4.	(end of life or end-of-life or end-stage or end stage or terminal cancer or advanced cancer or dying or palliative or hospice).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
5.	1 or 2
6.	3 or 4
7.	5 and 6
8.	(personal autonomy or paternalism or self concept or choice behavior or decision making or patient participation or refusal to participate or sick role).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
9.	(responsibility or duty or accountability or obligation).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
10.	8 or 9
11.	10 and 7
12.	(questionnaire or survey or interview or focus group or case stud* or observ* or grounded theory or narrative or thematic or experienc* or content analysis or ethnolog* or qualitative or quantitative or mixed methods).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
13.	11 and 12

Search History – Academic Search Complete

#	Query
---	-------

S13	S12 AND S11
S12	questionnaire OR survey OR interview OR focus group OR case stud* OR observ* OR grounded theory OR narrative OR thematic OR experienc* OR content analysis OR ethnolog* OR qualitative OR quantitative OR mixed methods
S11	S10 AND S7
S10	S8 OR S9
S9	responsibility OR duty OR accountability OR obligation
S8	personal autonomy OR paternalism OR self concept OR choice behavior OR decision making OR patient participation OR refusal to participate OR sick role
S7	S5 AND S6
S6	S3 OR S4
S5	S1 OR S2
S4	end of life OR end-of-life OR end-stage OR end stage OR terminal cancer OR advanced cancer OR dying OR palliative OR hospice
S3	palliative care OR palliative medicine OR terminal care OR hospice care
S2	cancer
S1	Neoplasms

Search History – CINAHL

Search ID#	Search Terms	Search History: CINAHL
<input type="checkbox"/>	S13	S11 AND S12

<input type="checkbox"/>	S12	questionnaire OR survey OR interview OR focus group OR case stud* OR observ* OR grounded theory OR narrative OR thematic OR experienc* OR content analysis OR ethnolog* OR qualitative OR quantitative OR mixed methods
<input type="checkbox"/>	S11	S10 AND S7
<input type="checkbox"/>	S10	S8 OR S9
<input type="checkbox"/>	S9	responsibility OR duty OR accountability OR obligation
<input type="checkbox"/>	S8	personal autonomy OR paternalism OR self concept OR choice behavior OR decision making OR patient participation OR refusal to participate OR sick role
<input type="checkbox"/>	S7	S5 AND S6
<input type="checkbox"/>	S6	S3 OR S4
<input type="checkbox"/>	S5	S1 OR S2
<input type="checkbox"/>	S4	end of life OR end-of-life OR end-stage OR end stage OR terminal cancer OR advanced cancer OR dying OR palliative OR hospice
<input type="checkbox"/>	S3	palliative care OR palliative medicine OR terminal care OR hospice care
<input type="checkbox"/>	S2	cancer
<input type="checkbox"/>	S1	neoplasms

Appendix L: Data Extraction Form

HEADING / SUB-HEADING	TO BE COMPLETED BY REVIEWER
Bibliographic Details <i># in Endnote</i> <i>Author(s)? Journal/Website? Year?</i>	
Eligibility 1) <i>Study participants are aged 18 years and older?</i> 2) <i>Participants have advanced cancer (defined as progressive, incurable, locally recurrent or metastatic malignancy, with an estimated life expectancy limited to 12 months or less)?</i> 3) <i>Study reports on responsibility (defined as the state of being accountable for, bearing a duty, or feeling an obligation towards something or someone)?</i>	
Type of Study <i>Empirical study?</i> <i>Quantitative?</i> <i>Qualitative?</i>	
<u>Study Focus and Methods</u>	
1. Aim <i>Study purpose?</i>	
2. Research Questions <i>What are the study objectives?</i>	
3. Data collection methods <i>What data collection methods used?</i>	

<p>4. Sample characteristics</p> <p><i>Who are the participants?</i></p>	
<p>5. Context and setting</p> <p><i>Geographical location? Care setting?</i></p> <p><i>Over what period of time?</i></p>	
<p>6. Participant perspectives</p> <p><i>What are the participants' experiences?</i></p>	
<p>7. Approaches to data analysis and interpretation</p> <p><i>How are data analyzed?</i></p> <p><i>What is the context for analysis?</i></p> <p><i>Is analysis framed by extant theory?</i></p>	
<p>8. Key Study Findings</p> <p><i>What are the study's outcomes?</i></p> <p><i>What are implications of study as a whole for theory?</i></p> <p><i>How does this fit within the new theoretical framework?</i></p>	
<p><u>Factors Specific To Theoretical Framework</u></p>	
<p>Maintaining Responsibility</p> <p><i>How does the study frame this concept?</i></p> <p><i>What are participants' experiences of this concept?</i></p>	
<p>1. Maintaining Responsibility</p> <p><i>Are any of these aspects of the core category explored by the study? If so, how?</i></p>	

a. No Matter How Small	
b. Critical Threshold	
c. Downsizing	
2. Responsibilities <i>Are any of these aspects of the core category explored by the study? If so, how?</i>	
a. Provision for Self (Self-Care, Self-Management of Health, Self-Sufficiency)	
b. Key Relations (Caregiver, Spouse, Parent, Grandparent, Child)	
c. Community (Vocation, Society)	
3. Benefits <i>Are any of these benefits of the core category explored by the study? If so, how?</i>	
a. Purpose/Contribution	
b. Identity	
c. Accomplishment	
d. Locus of Control	
e. Lack of Responsibility and Poor Quality of Life	
4. Conditions <i>Are any of these conditions of the core category explored by the study?</i>	

<i>If so, how?</i>	
a. Understanding of illness	
b. Symptom Burden	
c. Physical Functioning	
d. Disease and Symptom Treatment Strategies	
e. Day-to-Day Fluctuations	
f. Acute Stressors	
g. Environment Layout	
h. Person Supports	
i. Equipment Supports	
5. Mechanisms <i>Are any of these mechanisms of the core category explored by the study?</i> <i>If so, how?</i>	
a. Delegating versus Transferring	
b. Goal-Setting	
c. Day-to-Day Routine	
d. Path of Least Resistance	
e. Pacing	

f. Activity	
6. Other <i>Does the study explore factors not listed above but that are related to the Theoretical Framework?</i>	
7. Links to Related References <i>Are there related references to follow-up?</i>	
Reviewer Comments	